Promoting Resiliency in Families of Individuals Diagnosed with an Autism Spectrum Disorder: The Relationship between Parental Beliefs and Family Adaptation

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PROMOTING RESILIENCY IN FAMILIES OF INDIVIDUALS DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER: THE RELATIONSHIP BETWEEN PARENTAL BELIEFS AND FAMILY ADAPTATION

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Abstract

Promoting Resiliency in Families of Individuals Diagnosed with an Autism Spectrum Disorder: The Relationship between Parental Beliefs and Family Adaptation

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Comprehensive and collaborative intervention practices with individuals diagnosed with an autism spectrum disorder (ASD) recognize the essential role of the family in effective, long-term treatment of ASDs (e.g., National Research Council, 2001). While some research has focused on the experiences of families of individuals diagnosed with an ASD, there exists a need to better understand what factors detract from or facilitate the family's ability to adapt to their circumstances. Guided by the FAAR model (e.g., Patterson, 1989, 2005) and the Family Systems-Illness Model (e.g., Rolland, 1994, 2003), this current study examined the relationship between two demands or risk factors (i.e., the perceived severity of a child's ASD and the uncertainty related to a child's ASD), three capabilities or protective factors (i.e., optimism, mastery beliefs, and control beliefs), and the family's adaptation to their family member's ASD (i.e., family quality of life). Parents (N=207) of children diagnosed with Autism, PDD-NOS, or Asperger's Syndrome completed a self-report questionnaire assessing perceived ASD severity, the uncertainty regarding their child's ASD, the participant's optimism, mastery, and control beliefs, and the family's quality of life. Results demonstrated that the perceived severity of the child's ASD, the uncertainty related to the child's ASD, dispositional optimism, sense of coherence, and professional-related health locus of control are factors that

significantly influence the family's overall quality of life. In addition, dispositional optimism and sense of coherence were found to mediate the relationship between the identified demand factors and the family's quality of life. Results suggest that perceived severity and uncertainty regarding a family member's ASD are demands that have important implications for the family. Additionally, results suggest that optimism and mastery beliefs can play a positive, complex role in the family's adaptation to a family member's ASD. Finally, the results of this study suggest that control beliefs may act in complex and different ways than expected. Theoretical considerations and implications for practice and future research are discussed.

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When my eldest son, Colin, was diagnosed with an ASD, I was unsure if I would be able to finish my degree. My world radically changed; those involved in my world radically changed. However, through his and our family's growth, I found grounding in my values and beliefs, worldviews that I value dearly. To my parents, thank you for your continual support. To my children, thank you for your smiles, hugs, laughter and reminders of what is important in life. To my husband, my rock and best friend, thank you for being you.

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CHAPTER 1

Introduction

Over the past decade, the United States has witnessed an astounding increase in the number of children diagnosed with an autism spectrum disorder (ASD). Historically, the Centers for Disease Control (CDC) reported the prevalence of autism to be 4 - 5 per 10,000 children (approximately 1 in every 2000). In February, 2007, this prevalence rate was further revised to 1 in every 150 children (Centers for Disease Control and Prevention, 2007). Given that ASDs are biologically-based, life-long disabilities with no known cure (e.g., Bristol, 1985; Dykens & Volkmar, 1997; Schopler & Mesibov, 1987), this increase has profound public policy, intervention, and treatment implications. While the long term prognoses of children diagnosed with these disorders remain unclear (Coplan, 2003; Howlin, Goode, Hutton, & Rutter, 2004), research consistently demonstrates that children diagnosed with an ASD's potential for positive outcomes is increased when these children receive early and intensive interventions and treatment gains are generalized across contexts (e.g., Erba, 2000; National Research Council, 2001).

Many aspects help facilitate positive outcomes in individuals diagnosed with an ASD. One such aspect may be the family context. The general literature on child and adolescent mental health highlight the relationship between child treatment outcomes and the family context. For example, positive mental health treatment outcomes for the child or adolescent can be heavily dependent upon caregivers' motivation and participation in the treatment process (e.g., Morrissey-Kane & Prinz, 1999). Caregiver cooperation,

participation, willingness to change, and positive views towards their child's treatment are also vital factors influencing children's engagement in treatment (e.g., Frankel & Simmons, 1992; Gould, Shaffer, & Kaplan, 1985; Pekarik & Stephenson, 1988; Singh, Janes, & Schechtman, 1982). As this literature also highlights, treatments that focus solely on the child, without addressing the child's context, have had limited lasting impact (Weisz, Weiss, & Donenberg, 1992).

Within the ASD literature, the majority of research on treatment outcomes has focused on factors related to the diagnosed individual (e.g., Howlin, 2005). Less research has focused on either the family context or the interplay between the individual and the family context. This could be the result of the negative role parents' were historically assigned in the etiology of autism (Marcus, Kunce, & Schopler, 2005). Research over the past 30 years, however, have effectively debunked this myth of the "refrigerator parent" (Bettelheim, 1967), and currently support the conceptualization of ASDs as biologically-based neurodevelopmental disorders whose etiology is the result of a variety of potential risk factors (Dykens & Volkmar, 1997; Schopler & Mesibov, 1987). As the conceptualization of the family's influence on the etiology of ASDs has changed, families have increasingly been recognized as essential in effective treatment of ASDs (Lovaas, 1987; Marcus & Schopler, 1989; Volkmar, Cook, & Pomeroy, 1999) and collaborative work with families have become a standard of comprehensive practice (Marcus, Kunce, & Schopler, 2005; National Research Council, 2001; Schopler & Mesibov, 2000).

Concurrent with this historical shift in researchers' and practitioners' views of families of individuals diagnosed with an ASD is the use of systems-focused theories to understand development and change. According to modern developmental systems theories (e.g., Bronfenbrenner, 1986; Ford & Lerner, 1992; Lerner, 1991; Lerner, Walsh, & Howard, 1998), optimal development of the individual is dependent not only upon aspects solely related to that individual, but also the contexts, such as the family, within which the individual exists. This holds true even for children managing chronic illnesses or disabilities. An increasing body of literature with this population has provided evidence that the outcomes of the child with an illness or disability is not only dependent upon features related to the particular illness or disability, or characteristics of that individual child, but also features of the family system (Patterson, 2005). Structural aspects of the family, (e.g., age of the parents, family size, and marital status), parental mental health, quality of family members' relationships and support, and marital or family conflict can impact child adaptation to illness/disability and child developmental outcomes (e.g., Gortmaker, Walker, Weitzman, & Sobol, 1990; Hauser-Cram et al., 1999; Robbins, Dunlap, & Plienis, 1991; Silver, Stein, & Bauman, 1999; Thompson, Auslander, & White, 2001; Weihs, Fisher, & Baird, 2002; Williamson, Walters, & Shaffer, 2002). Thus, this literature suggests that the family context is a powerful aspect in promoting positive outcomes in individuals faced with a variety of chronic conditions, including ASDs.

In addition to describing how the family promotes positive outcomes in the individual diagnosed with an ASD, developmental systems theories (e.g.,

Bronfenbrenner, 1986; Ford & Lerner, 1992) recognize that the individual's ASD also has implications for the family. Chronic illness or disability of any type is a stressor that impacts the entire family unit, introducing unique challenges that have the potential to affect all family members' health, well-being, general resources, and experiences across the life span (Patterson, 2005; Summers et al., 2005; Turnbull, Turnbull, Erwin, & Soodak, 2006). This appears true for families of individuals diagnosed with ASDs as well. The majority of past research that has focused on family members of individuals diagnosed with an ASD has highlighted the negative impacts a family member's ASD has upon individual family members' functioning. For example, studies have demonstrated that parents of individuals diagnosed with an ASD experience greater amounts of negative outcomes, such as stress, anxiety, depression and marital difficulties, than parents of typically developing children or even parents of children with other types of developmental delays (e.g., Dumas, Wolf, Fisman, & Culligan,1991; Hastings & Brown, 2002; Hastings et al., 2005a; Higgins, Bailey, & Pearce, 2005; Holroyd & McArthur, 1976; Plant & Sanders, 2007; Rodrigue, Geffken, & Morgan, 1991; Sanders & Morgan, 1997).

Recent literature on families of individuals diagnosed with an ASD or other childhood chronic illnesses and disabilities have noted that these chronic conditions can also have positive individual implications for some families (e.g., Kausar, Jevne, & Sobsey, 2003; Krauss & Seltzer, 2000; Marcus, Kunce, & Schopler, 2005). Across a variety of studies, parents have noted positive aspects or changes resulting from their child's illness or disability, including parents' personal psychological growth (e.g.,

greater inner strength, increased self-efficacy), increased advocacy skills, improved relations with others, and positive changes in philosophical or spiritual values (e.g., an increased acceptance of difference, an increased ability to see life from others' perspectives, increased compassion, changes in values) (Krauss & Seltzer, 2000; Patterson, Garwick, Bennett, & Blum, 1997; Patterson, Holm, & Gurney, 2004; Patterson & Leonard, 1994; Scorgie, Wilgosh, & McDonald, 1996; Scorgie & Sobsey, 2000).

The foci of these studies are congruent with the current intervention and treatment goals with families of individuals diagnosed with ASD, including promoting positive family adjustment through helping families develop or increase concrete skills, knowledge, and/or resources (Marcus, Kunce, & Schopler, 2005). While the practice of building concrete capacities and abilities of families of individuals diagnosed with an ASD is vitally important, for some families, interventions that are focused solely on capacity-building may not have the desired effect of helping to promote the family's resilience or helping the family adapt to their circumstances. Families of individuals diagnosed with ASDs display varying levels of cooperation and participation in treatment (Bristol & Schopler, 1984), a wide range of family practices and beliefs (Bristol & Schopler, 1984), varying perceptions of individual and family needs (Bristol, 1985), and different overt or covert assumptions about the nature of the child's ASD (Bristol, 1985). Thus, there exists a need to better understand what factors or beliefs detract from or facilitate the family's ability to adapt to their circumstances, so that these areas can be targeted in comprehensive intervention and treatment strategies.

To this end, theories related to the broader literature on chronic disability and illness may be constructive. For this current study, two theories were found to be particularly useful as conceptual frames within which to understand the experiences and outcomes of families of individuals diagnosed with an ASD. The first is the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988, 1989, 2002, 2005; Patterson & Garwick, 1994), which posits that family adaptation to a stressful condition, such as a family member's ASD, is dependent upon the family's demands, the family's capabilities, and the beliefs the family hold regarding the stressful condition. The second, the Family Systems-Illness Model (Rolland, 1984, 1987, 1994, 1999, 2003), is a family-systems theory that focuses on specific aspects, such as characteristics of different chronic illness/disabilities and beliefs family members hold about their experiences, which impact the functioning of families faced with chronic illness and disability.

When these two theories are used as frames within which to organize the existing family-focused literature on ASDs, three main themes arise. First, unlike the majority of the past research on family outcomes in families of individuals diagnosed with an ASD or other chronic illnesses or diseases, a greater focus should be given to what promotes positive family adaptation to this particular chronic disability (Bristol, 1985). Promoting positive family adaptation not only has the potential to influence the individual diagnosed with an ASD's treatment outcomes, but also creates a healthier environment for all family members. This is particularly important given the life long impact ASDs, and more broadly chronic illnesses and disabilities, have upon such aspects as long-term family

functioning, living situations and provision of care (e.g., Cummins, 2001; Gray, 2002, 2006). Once the focus is shifted to that of promoting positive adaptation, then the corollary question no longer is what other negative outcomes exist for families, but rather how do practitioners best support lifelong resilience in these families? To this end, this study chose to focus on family adaptation as its outcome and specifically utilizes the construct of family quality of life to represent family adaptation. As discussed further in Chapter 2, an individual's optimal development and quality of life is related to the beliefs and quality of life of those people around them (Poston et al., 2003). Thus, overall family quality of life and ability to adapt to their circumstances is an important factor that has implications on the long-term promotion and sustainability of the optimal development of the individual diagnosed with an ASD and his/her family.

Second, both the FAAR model (Patterson, 1988, 1989, 2002, 2005) and the Family Systems-Illness Model (Rolland, 1984, 1987, 1994, 1999, 2003) posit that the beliefs that family members, particularly parents, have are critical aspects in the family's adaptation process. These family beliefs can have a significant impact on the family's perception and management of their capabilities and demands, ability to balance capabilities and demands, ability to access additional resources, as well as their overall adaptation and resilience (Hawley, & DeHaan, 1996; King et al., 2006; McCubbin & McCubbin, 1993; Patterson, 2005; Walsh, 1998). The majority of current research on families of individuals diagnosed with an ASD tends to focus on the concrete capabilities or demands of individual family members, such as type of coping skills, amount of material resources, and support utilization, which can either reduce or increase the

experience of negative outcomes. Comparatively little research with this population, however, has examined the role that family beliefs play in either directly or indirectly influencing outcomes. This is surprising, given that the research on child and adolescent mental health treatment suggests that parental beliefs, such as personal control, competence, and expectations for child improvement, have direct implications on parental involvement in child treatment, perseverance with treatment, and parents' conceptualizations of failure and successful experiences (Morrissey-Kane & Prinz, 1999). Therefore, this study attempts to advance the literature on families of individuals diagnosed with an ASD by examining the direct influence specific family beliefs have upon the family's adaptation. The family beliefs chosen for examination in this current study include parents' optimism, their control beliefs regarding their child's ASD, and their feelings of mastery. As will be discussed further in Chapter 2, all three of these specific beliefs were chosen because of the relatively little research available on them with families of individuals diagnosed with an ASD as well as the theorized importance they have upon overall family functioning.

In addition to the direct influence family beliefs can have on overall family adaptation, family beliefs are also thought to indirectly influence the relative impact that risk factors have upon outcomes (Patterson, 2002, 2005; Rolland, 1994, 2003). That is, these beliefs shape how families define and perceive their capabilities, the nature of the demands placed upon them, as well as their ability to effectively adapt. Thus, to test the extent to which family beliefs have an indirect influence on the relationship between risk factors and family adaptation in families of individuals diagnosed with an ASD, this

study also examines the extent to which family beliefs act as mediators for specified risk factors. The risk factors chosen for this current study are the uncertainty and perceived severity of the child's ASD. Given the variability of day to day and overall symptom expression, unpredictable individual outcomes, and range of severity inherent to ASDs, these two risk factors have particular relevance with respect to the family's experience.

In conclusion, this study attempts to inform the literature on families of individuals diagnosed with an ASD by examining the role of family beliefs in the family's adaptation to a child's ASD. Given the potential importance of the family in child treatment outcomes, the impact ASDs can have upon the family unit, and the need to support life long resilience in this population, this study assumes that family adaptation, as measured by family quality of life, is an outcome that should be focused upon in the ASD literature. Based upon the FAAR model (Patterson, 1988, 1989, 2002, 2005) and the Family Systems-Illness Model (Rolland, 1984, 1987, 1994, 1999, 2003), this study expects that a direct relationship between family beliefs and family adaptation exists. Finally, given the theorized indirect impact family beliefs can have on the relationship between demands placed upon the family and family adaptation, this study will also examine the extent to which family beliefs mediate the relationship between demands (i.e., uncertainty and perceived level of severity) and the family's quality of life.

The next chapter will provide background information and further context for this study by reviewing and critiquing the relevant literature.

CHAPTER 2

Literature Review

This chapter begins by reviewing a brief history of ASDs and their diagnostic criteria. Next, it will detail two specific theories, the Family Adjustment and Adaptation Response (FAAR) model and the Family Systems-Illness Model, and outline how these specific theories conceptually guide this study. The remainder of this chapter will provide definitions and review the literature on this study's specific variables. These variables are grouped into three main classifications based upon those suggested by the FAAR model. First, two specific family demands selected for this study (i.e., uncertainty and perceived severity) will be defined and explored. Next, three specific family beliefs (i.e., optimism, control, and mastery) will be defined and explored. Then, the outcome variable of family adaptation (i.e., family quality of life) will be defined and explored. This chapter then ends with a summary of the literature and the hypotheses of this current study.

Autism Spectrum Disorders

The diagnosis and treatment of autism has changed dramatically over the past 65 years, reflecting changing knowledge and understanding of this disorder. While a comprehensive review of these historical changes is prohibitive in this current study, some understanding of the evolution of beliefs regarding autism and its treatment is vital to contextualize the current state of treatment, involvement of families, and residual impacts of historical beliefs. Therefore, this section will briefly review the history of autism and current diagnostic criteria.

Brief History of Autism

The term “autism” was first utilized by Leo Kanner in his 1943 seminal work describing children with disturbances of affective contact (Kanner, 1943). Basing his work on the developmental theory and work of Gesell, Kanner described a group of children that he believed lacked the ability to successfully navigate and interact in the social world, effectively isolating them socially. Kanner termed this group as “autistic” (Kanner, 1943). Kanner also noted other clinical features of these children, including profound difficulties in communication, sensitivity to stimulation in the environment, and resistance to change (Volkmar & Klin, 2005). Even today, Kanner’s observations continue to illustrate important clinical characteristics of autism spectrum disorders (Mesibov, Adams, & Schopler, 2000).

While Kanner’s observations highlighted important core clinical factors, several of Kanner’s conclusions have been discounted over time. First, while Kanner originally believed that most children with autism have average to above-average intelligence and the potential for normal language development, modern studies estimate that the average IQ score of children diagnosed with autism is approximately 50 and at least 40 % do not develop functional expressive language (Mesibov, Adams, & Schopler, 2000). Second, while Kanner posited that autism was more prevalent in highly educated or affluent families, current studies suggest that autism’s prevalence is distributed proportionally across educational level, social class, and race (Mesibov, Adams, & Schopler, 2000).

Finally, while Kanner implicated inadequate parenting in autism, this belief has been discredited (Mesibov, Adams, & Schopler, 2000; Volkmar & Klin, 2005).

From Kanner's observations and postulations, a great debate began regarding the causes of autism. A proponent of psychoanalytic views of autism etiology, Bruno Bettelheim theorized that autistic children were the product of emotional deprivation from non-nurturing parents, particularly what were termed "refrigerator mothers" (Bettelheim, 1967). He argued that the only way to effectively treat an autistic child was to remove them from their parents, who were the cause of their disorder, and provide them with nurturance (Mesibov, Adams, & Schopler, 2000). While the impact of parental behaviors upon the etiology of autism has been conclusively discredited, this notion of parental blame for the disorder unfortunately continues to exist both in certain cultures and in some families' understanding of their experience (Mesibov, Adams, & Schopler, 2000; Volkmar & Klin, 2005).

At the same time that Bettelheim made his claims regarding the cause of autism, beliefs regarding the organic nature of autism began to be formulated. By 1969, Kanner retracted his views of parental cause in light of the growing evidence of biological and genetic influences (Mesibov, Adams, & Schopler, 2000). While all current conceptualizations of autism etiology acknowledge its causes to be organically based, rather than socially derived, research continues to elucidate the pathways or specific mechanisms by which children develop autism and related disorders (Rutter, 2000).

Diagnostic Criteria

The diagnostic criteria for autism have undergone much revision during the 60 years since Kanner's work (for a full account of the diagnostic history of autism, please see Volkmar & Klin, 2005). Currently, autism is believed to be a complex neurobiological disability that appears within the first three years of life. It impacts the development and typical functioning of the brain, particularly in three main areas: 1) communication, 2) social interaction, and 3) patterns of behavior, interests, and/or activities (American Psychiatric Association, 2000). As a "spectrum" disorder, autism affects each individual differently and each of the three main areas to varying degrees. Therefore, expression of symptomatology may appear extremely different from one child to the next.

Autism is one of five disorders that fall within the overarching category of Pervasive Developmental Disorder (PDD), also commonly referred to as autism spectrum disorder (ASD). The other disorders include Asperger Syndrome, Childhood Disintegrative Disorder (CDD), Rett's Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). As a group, Pervasive Developmental Disorders or ASDs are related through their early-onset of impairments in reciprocal social interaction to such an extent that it deviates markedly from what is expected from typically developing peers (American Psychiatric Association, 2000). Each disorder, however, differs in the presence or severity of communication impairments or stereotyped behaviors, interests, and activities (American Psychiatric Association, 2000). Details

regarding diagnostic criteria can be found in the Diagnostic and Statistical Manual – IV (American Psychiatric Association, 2000).

Theories Guiding Current Study

As collaborative work with families of individuals diagnosed with an autism spectrum disorder (ASD) has increasingly become a standard of comprehensive practice, it is important to identify appropriate systems-focused theories to help guide effective family-level intervention and treatment. Theory provides researchers and practitioners with a conceptual map, informing the "what," "why," and "how" of inquiry, prevention and intervention. It also dissuades the researcher and practitioner from utilizing their own personal assumptions and beliefs in the interpretation, or assigned meaning, given to observations, statistical findings, and/or families' narratives. With that said, one must also continuously be cognizant of the limitations that theories have, particularly the impact of historical, cultural, biological and contextual meanings upon our understanding and definition of "problems" and "solutions." For example, Bettelheim's (1967) conclusions were embedded within the era of psychoanalytic and deficit-focused views of autism, as well as informed by the cultural and historical views of "normal" families. However, given the current, and continuously evolving biological, contextual, and developmental knowledge regarding ASDs, theories that are multidimensional, strength-focused, and amenable to the constructivist view of "normal" families and their experiences must necessarily be adopted.

As counseling psychologists and other developmentally-focused practitioners recognize, developmental systems theories, such as developmental contextualism (Ford & Lerner, 1992; Lerner, 1991; Lerner, Walsh, & Howard, 1998), can be beneficial as overarching organizing frameworks to understand the complexities associated with optimum, or less-than-optimum, developmental outcomes in families of individuals diagnosed with an ASD. For example, developmental contextualism posits that the development of the individual is influenced by four key aspects: a) context, b) bio-psycho-social levels of organization within an individual, c) development across the lifespan, and d) the impact of risk and protective factors (Lerner, 1991). *Context* refers to the multiple levels of organization or systems (e.g., family, community, society, etc.) in which an individual exists and with which the individual interacts in a dynamic way (Ford & Lerner, 1992). *Bio-psycho-social* emphasizes the interaction between multiple and integrated levels of organization within an individual (Ford & Lerner, 1992). Development across the *lifespan* notes that development is a continual process that occurs from birth until death and is embedded within a historical context. As such, development functions as a consequence of prior developmental shifts and changes, not in isolation (Ford & Lerner, 1992). Finally, a developmental contextual approach to change highlights the factors that can lead to both negative outcomes (*risk*) and factors that promote positive outcomes despite adversity (*resilience*) (Lerner, 1991).

In adopting a developmental systems-informed view of families of individuals diagnosed with an ASD, treatment of ASDs is broadened from an individual and remedial-focused view to a more dynamic, contextual and temporal view of optimal

change. Interventions thus shift to overtly recognize the different contexts, or systems involved with the individual, their dynamic relationship with the individual, and the factors within this dynamic relationship that either promote or detract from optimal development and treatment. This view thus recognizes that, unlike past unidimensional conceptualizations of ASDs, children diagnosed with an ASD have a considerable range of biological, psychological, and social aspects that need to be taken into consideration when trying to achieve the best 'fit' between the child diagnosed with an ASD and a particular treatment. In addition, developmental contextualism promotes the idea that the child diagnosed with an ASD is embedded within his/her context and is an active participant in constructing his/her optimal outcomes. As such, this view of the child and his/her interaction with his/her context provides a rationale for utilizing both individual and context-focused interventions. A developmental contextual view of a child diagnosed with an ASD's optimal development also supports viewing treatment as a lifelong process that will necessarily address different needs and have different foci over the course of that child's life. These treatment needs and foci will include both short and long-term goals that focus on helping the ASD child achieve an optimal quality of life, as defined by the child, his/her family and their personal and cultural beliefs and values. Finally, this conceptual view also notes the importance of understanding specific risk and protective factors that promote resilience in children diagnosed with an ASD and their families, so that interventions can target these factors.

Utilizing a developmental systems-informed view of children with disabilities has been advocated in the past (e.g., Bristol, 1984; Bristol & Schopler, 1984; Glidden, 2002;

Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Seligman, 1999) and arguably has lead to the increased attention given to contextual and relational factors that lead to better outcomes with this population. However, developmental systems-focused theories, such as developmental contextualism, are broad, general theories. As such, other theories that are domain-specific must also be utilized for smaller unit analysis.

An underlying assumption of this current study is that, for optimal long-term outcomes to occur in the child diagnosed with an ASD, the family context in which that child is embedded must also be an overt target for intervention. Thus, this study chose to rely upon two family-focused theories, the Family Adjustment and Adaptation Response model (FAAR; Patterson, 1988, 1998, 2002, 2005; Patterson & Garwick, 1994) and the Family Systems-Illness Model (Rolland, 1984, 1987, 1994, 1998, 1999, 2003), to help inform the current study's areas of inquiry. The FAAR is a process model that combines resilience theory with family stress theory. It elucidates the process by which families adapt to stress or crisis through their management of the demands placed upon them (i.e., risk factors), the family's capabilities (i.e., protective factors), and family beliefs. As such, this theory is consistent with the developmental contextual focus on risk and resilience, as well as its focus on life-long optimal development or adaptation.

The Family Systems-Illness Model (Rolland, 1984, 1987, 1994, 1999, 2003) is a family systems theory used to guide mental health services with families of individuals with chronic illnesses or disabilities. It elucidates several key aspects of the illness or disability experience, including illness or disability-specific characteristics that impact family functioning (termed psychosocial typology of illness), time phases of illness or

disability across the life span, as well as family relational patterns and family beliefs that either hinder or facilitate adaptation to illness/disability demands (Rolland, 1994, 2003). As with the FAAR model, the Family Systems-Illness Model is consistent with a developmentally-informed view of chronic illness or disability in that it recognizes the importance of the interactive relationship between the chronic condition, the individual, and the family across time in promoting health and well-being (Rolland, 1994).

Separately, both of these theories have gained greater acceptance within the chronic illness and disability literature (e.g., Marshak, Seligman, & Prezant, 1999; Seligman & Darling, 2007), but have received little to no attention in the literature specifically focused on ASDs. Combined, the FAAR model and the Family Systems-Illness Model not only help identify potentially key family risk and resiliency factors that impact individual and family adaptation, but also illuminate potential intervention foci to help foster optimal adaptation and functioning. Therefore, this next section will review both theories and detail how these theories were used as conceptual frameworks for this current study.

Family Adjustment and Adaptation Response (FAAR) Model

At its core, the FAAR model is a combination of aspects from resilience theory and family stress theories. Resilience theory examines the factors and processes by which an individual manifests competence in overcoming adversity (Masten & Coatsworth, 1998). Within this definition of resilience, competence is thought of as a pattern of effective adaptation in one's context or environment, with success defined as either accomplishment in broad developmental tasks or in specific domains of achievement

(Masten & Coatsworth, 1998). While once considered to be exhibited by only special, or 'invulnerable,' individuals, resilience is now commonly accepted to be an ordinary, dynamic process (Masten, 2001).

The concept of resilience primarily arose from studies examining children who functioned well despite exposure to stress and adversity (e.g., Garmezy, 1991; Masten, 1994; Werner & Smith, 1992), although other disciplines, such as sociology and epidemiology, also contributed to this concept (e.g., Antonovsky, 1987; Cassel, 1976). These studies concluded that individuals displayed resilience if they were able to function competently after being exposed to significant risk (Patterson, 2002). In an effort to promote resilience in individuals, several aspects, at various contextual levels, were identified as characteristics of resilient individuals. Individually, resilient children were noted to often display good intellectual functioning; an appealing, sociable, or easygoing disposition; self-efficacy, self-confidence, or high self-esteem; talents; and faith (Masten & Coatsworth, 1998). Several contextual factors were also identified as important in fostering individual resilience, including close relationships to a caring parental figure; a parenting style that included warmth, structure, and high expectations; socioeconomic advantages; connections to extended family; bonds to prosocial adults outside the family; connections to prosocial organizations; and attendance at effective schools (Masten & Coatsworth, 1998). It should be noted that these qualities may not be adaptive for all conditions and that different vulnerabilities and protective factors and processes may occur over the course of one's lifespan.

Just as the concept of individual resilience emerged from studies regarding the ability of individuals to overcome stress and adversity, the concept of family resilience emerged from studies focusing on the ability of families to manage stress and cope with adverse situations or experiences (Patterson, 2002). Family resilience can be thought of as the family's ability to successfully manage difficult or challenging life circumstances (Walsh, 1998). As such, family resilience can be defined as "characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations' (McCubbin & McCubbin, 1988, p.247). As with the research on individual resilience, significant stressors, or a "pile-up" of several different stressors, can impact a family's current functioning and ability to successfully adapt to subsequent problems (Boss, 2001; McCubbin & Patterson, 1983).

Similar to the literature on family resilience, family stress theories evolved from research examining the conditions under which families are adversely affected by stressful circumstances (Patterson, 1989). The first major family stress theory was Hill's ABCX family crisis model (Hill, 1949, 1958), a model that evolved from examining the impact of separation and reunification due to war upon the family. Hill posited that a stressor event ('A') interacted with the family's crisis-focused resources ('B') which interacted with how the family defined the event ('C'), producing the crisis ('X') (Hill, 1958). During the 1970s, family stress researchers utilizing Hill's ABCX model suggested additional factors that influence the family's adaptation to crisis (Patterson, 1989). As a result, the Double ABCX model was developed (McCubbin & Patterson, 1983). This model adapted the original ABCX model by including additional factors,

such as demand pile-up (i.e., multiple demands upon the family), the role of coping strategies in managing these demands, and the role of family perceptions in influencing adaptation (McCubbin & Patterson, 1983).

The Family Adjustment and Adaptation Response model (FAAR; Patterson, 1988, 1989, 1993, 2002, 2005; Patterson & Garwick, 1994) was created to incorporate key elements of the Double ABCX model (McCubbin & Patterson, 1983) into a process model that describes how families advance from pre-crisis adjustment to post-crisis adaptation (Patterson, 1989). This model is also an overt attempt to highlight the links between family stress models and family resilience theory (Patterson, 1988, 2002). The FAAR describes the process by which a family responds to a crisis by focusing on four main components, (i.e., family demands, family capabilities, family meaning, and adaptation) and their relationship with one another (Patterson, 1988, 1989, 2002).

According to the FAAR model, individual and family adaptation to a stressful condition is dependent upon the family's efforts to manage their demands, the family's capabilities to address these demands, and mediated or moderated by family beliefs or meanings (Patterson, 1989, 2005). In essence, demands and capabilities are balanced as if on a see-saw, under the umbrella of family beliefs or meanings. As family demands become increasing greater ("pile-up") or a major stressor event occurs, the family tips into crisis, or a state of disorganization and disruption (Patterson, 1988, 1989). From this state of disorganization, families attempt to adapt by restoring balance to their system (Patterson, 1988, 1989).

Family demands are conditions that produce change in the family through creating tension (Patterson, 1988, 1989). Demands consist of both stressors and strains which challenge the family's functioning. In this theory, stressors are defined as life events that occur at a particular time, while strains are conditions that do not have a discrete beginning (Patterson, 1989). The nature of these two types of demands influence how families address them; that is, while change is directed at managing a stressor, change is utilized to get rid of on-going strain (Patterson, 1989). Thus, the onset of a chronic health condition can be considered a stressor, while the residual tension felt from not being able to resolve the condition is considered a strain. Combined, demands include normative and non-normative stressors, ongoing family tensions, and minor daily hassles (Patterson, 2002). Demands persist until some family capability is direct towards addressing the demand (Patterson, 1989). Families typically manage multiple demands (also termed "pile-up") at one time. Given the necessity of prioritizing the resolution of different demands, there always exists some residue of strain that produces some level of stress within the family. Thus, it is understandable how 'little things' might compile to overwhelm the family's capability to manage these demands (Patterson, 1989).

Consistent with resiliency theory, demands can also be conceptualized as risk factors that negatively impact family functioning (Patterson, 2002). As with risk factors, demands exist on a variety of systemic levels, including individual, family, community, and society. For example, risks or demands that can negatively impact functioning in families faced with chronic health conditions include the family member's diagnosis, marital discord, stigma associated with the chronic condition, loss of social relationships,

and lack of policy or funding for appropriate research and treatment (Patterson, 2002). Just as risk factors can interact to negatively impact individual and family functioning, so too can the pile-up of demands (Patterson, 2002).

Family capabilities are those aspects that the family has available to meet a demand (Patterson, 1989). Family capabilities are defined in two categories: family resources (i.e., what a family has) and family coping behaviors (i.e., what a family does) (Patterson, 1989, 2002). Family resources can include concrete items or intangible characteristics or competencies (Patterson, 1989). Family coping behaviors are problem-solving behaviors that include explicit actions made by individuals or the collective family to reduce a demand (Patterson, 1989). Through utilizing their resources and coping behaviors, the family attempts to maintain or restore balance between its demands and capabilities.

As with demands, capabilities are also conceptually similar to protective factors within resilience theory (Patterson, 2002). Many of the resources and coping behaviors that Patterson identifies have also been identified within resilience theories as protective factors (Patterson, 2002). For example, both the stress literature and the literature on resilience have identified similar factors that promote positive outcomes, including intelligence, knowledge and skills, personality traits such as humor, physical health, emotional health, individual self-esteem, family cohesion and organization, boundaries, and communication skills (Masten & Coatsworth, 1998; Patterson, 1989; Walsh, 1998).

Family meanings or beliefs are considered to be critical mediators or moderators of family demands, capabilities, and overall family adjustment or adaptation (Patterson,

1988, 1989, 1993, 2002, 2005). Family meanings are beliefs held by individual family members as well as those held by the family as a whole. Family meanings are conceptualized to exist on three levels: how families define their demands and capabilities; how the family defines themselves as a family; and how the family views itself in relation to broader systems (i.e., family world view) (Patterson, 1993, 2005; Patterson & Garwick, 1994). These meanings are thought to impact how the family understands and responds to its exposure to risk and its ability to protect itself (Patterson, 2002). In essence, family beliefs or meanings influence the relative impact family capabilities and demands have upon the family's ultimate adaptation to crisis events.

Through shared family beliefs, families reduce the ambiguity and uncertainty regarding the demands they face and help in coordinating responses to the demands (Patterson, 2005). In addition, family beliefs or meanings help families interpret their reality and their assumptions, which in turn impact how they define their capabilities and demands, their crisis situation, and the actions they take to adapt to their situation (Patterson, 2005). Considered the core of family resilience (Walsh, 1998), the beliefs or meanings families hold can include optimism, relativism (i.e., living in the present), shared control (i.e., balancing individual control with trust in others), shared purpose, and collectivity (i.e., family as part of something larger than itself) (Patterson, 1989, 2005). In families faced with chronic illness or disability, family beliefs or meanings can also include how a family defines a chronic condition, strains associated with the condition, and the perceived resources the family has to manage the condition (Patterson, 2005).

The FAAR model posits that families flow in and out of two phases throughout their life cycles. The first, or adjustment, is the phase in which families utilize fairly stable patterns of interaction on a daily basis to balance their capabilities and demands (Patterson, 1988, 1989). This phase continues until demands significantly outweigh their capabilities, either due to the introduction of a stressor or through the pile-up of strains. When this occurs, the family experiences a state of crisis, a turning point for the family that induces a state of disorganization and disruption (Patterson, 1988, 1989). Crises are thought to produce significant changes in the family by facilitating either improved or poorer family functioning (Patterson, 1988, 1989).

The process by which families restore balance and organization after a state of crisis is called adaptation, the second phase of the FAAR model (Patterson, 1988, 1989). Adaptation itself has no one definition that is consistently used in the theoretical or empirical literature, though it is often defined as families doing well on a designated outcome measure, such as indices of stress, depression, or marital satisfaction. In the FAAR model, however, Patterson views adaptation as a process that results in restoring balance between families' capabilities and demands on two specific systemic levels: between individuals within the family unit, and between the family and the wider community (Patterson, 1988, 2002). Successful family adaptation, then, includes the promotion of both individual family member's optimal development, as well as the family unit's ability to successfully manage tasks across time (Patterson, 1988).

Patterson draws overt parallels between family adaptation and family resilience. Within the family resilience literature, resilience encompasses a family's ability to

successfully manage difficult life circumstances (Walsh, 1998). Within the FAAR model, positive family adaptation to crisis is similarly defined (Patterson, 1988, 1989, 2002). In families faced with chronic illness or disability, an additional aspect of family resilience or adaptation includes the family's ability to meet the needs of their vulnerable family member (Patterson, 2002). This aspect alone, however, cannot be considered an indicator of family resilience, given the potential for families to direct so many resources toward the vulnerable family member at the expense of meeting other family members' needs (Patterson, 2002).

This idea that successful adaptation necessitates both within system (i.e., family) and between systems (i.e., family and community) outcomes has very important implications for families of ASD individuals. By defining adaptation in this way, positive adaptation incorporates both individual and family functioning as treatment goals. While the promotion of positive gains in the individual diagnosed with ASD continues to be a significant focus of treatment, the resources of the family (e.g., time, financial, physical, emotional, etc.) that are allocated towards that individual is then balanced with the whole family's needs. This is especially important when, in families fearful of not doing enough for their family member diagnosed with ASD, the family overextends itself and becomes so involved in treatment that they ignore the rest of the family's needs, relationships, or experiences. Likewise, for families underinvolved in their ASD member's treatment, the individual and family's optimal adaptation may necessitate further family involvement and voice in treatment. Thus, by framing positive outcomes in this manner, successful

adaptation of the family becomes aligned with promoting optimal functioning of individuals within the overarching goal of optimal quality of life for the family.

In addition, the FAAR model highlights the connections between family functioning and its relationship with the community. These connections can be conceptualized in a variety of ways, such as positive, supportive relationships between the family and community members, including service providers. In addition, as many families are faced with finding appropriate services for their family member diagnosed with an ASD throughout that individual's lifespan, the extent to which a family can appropriately advocate for their family member diagnosed with an ASD's needs, competently navigate the various systems involved in their family member diagnosed with an ASD's treatment, as well as feel empowered to effect change at a variety of levels, gains overt importance. As Marcus and his colleagues note, by empowering families and conceptualizing them as active agents of change, positive outcomes can occur beyond solely the individual level (Marcus, Kunce, & Schopler, 2005).

Family Systems-Illness Model

Another theory guiding this study is the Family Systems-Illness Model (Rolland, 1984, 1987, 1998, 1994, 1999, 2003). The Family Systems-Illness Model (Rolland, 1984, 1987, 1998, 1994, 1999, 2003) is a family systems theory that focuses specifically on chronic illness and disability within the family unit. Typically, chronic health conditions entail long-lasting impacts upon an individual and their family, often requiring intensive treatments or changes in individual and family life styles, routines and relationships. While several developmental disabilities and disorders of childhood onset have also been

conceptualized as chronic illnesses or disabilities (e.g., Down syndrome, mental retardation), ASDs often elude this classification in the general vernacular. However, as a pervasive developmental disability, with its capacity for severe and long-lasting impact upon individual and family functioning, one can define ASDs as chronic disabilities as well (Gray, 1994). As a result, lessons learned from family systems work focusing on chronic disabilities can help inform work with families of individuals diagnosed with an ASD.

The Family Systems-Illness Model (Rolland, 1984, 1987, 1994, 1998, 1999, 2003) evolved from Rolland's observation that a systems perspective to chronic health conditions could increase the awareness of both the impact chronic disabilities have upon the family system and the importance of a strength-based approach to family work with this population. Rolland (1984, 1987, 1994, 1999) noted that early research on families who manage illness and disability tended to focus only on the individual patient, with family considerations limited to the "pathological" family factors associated with poor compliance with treatment recommendations and poor outcomes. This led practitioners to utilize paradigms that focused on dysfunctional family systems (Rolland, 1994, 1999). Since illness and disability can impact any family at any time, and therefore is more the norm than an abnormal experience, Rolland argued that understanding a family's ability to cope and adapt successfully to these experiences should emerge from a more strengths-based approach that focuses on normal family processes (Rolland, 1994, 1999).

As a result, Rolland (1984, 1994) developed the Family Systems-Illness Model to be a comprehensive clinical model for working with families faced with illness and

disability. Drawing from family resilience theory (Walsh, 1998, 2002, 2003) and family systems theories (e.g., Carter & McGoldrick, 1998; Nichols & Schwartz, 2000; Rolland & Walsh, 1996), Rolland based his model on a strength-oriented perspective that views family relationships as resources in dealing with illness and disability, while also placing greater emphasis on resilience and growth, rather than risks and liabilities (Rolland, 1994, 1999). This model emphasizes three main areas: 1) psychosocial types of illness and disability; 2) developmental phases; and 3) key family system variables influencing outcomes (Rolland, 1984, 1987, 1994, 1999). Inherent in this model is the 'goodness of fit' between the psychosocial demands of a particular illness or disorder and the strengths of a particular family (Rolland, 1984, 1994, 1999). While a comprehensive examination of this model's many facets is prohibited in this current review (please see Rolland, 1994 for in-depth examination), two main aspects of this model are particularly salient to this current study. The following section reviews these two aspects, namely the psychosocial typology of illness and family systems variables influencing outcomes.

Rolland (1984, 1994) developed the psychosocial typology of illness in order to better understand how different types of illness or disability might produce different needs and family treatment foci. Rolland argues that chronic conditions can be grouped according to key biological similarities and differences that produce specific chronic illness or disability related demands for families (Rolland, 1994, 1999). This typology is based on five categories of factors, all on a continuum, that are hypothesized to impact the nature of the tasks faced by families at different time phases of a wide range of illnesses or disabilities (Rolland, 1984, 1994). These five categories include: the onset, level of

uncertainty or predictability of a particular illness or disability, course, outcome, and the degree of incapacitation (Rolland, 1994, 1999).

Rolland noted that the type of *onset*, i.e., gradual or acute, is an important factor in working with families faced with illness or disability. Acute onsets reflect an immediate expression of symptomology and is often unexpected by the individual or his/her family (Rolland, 1984, 1994). In gradual onsets, the symptomology of the disease has been recognized by the family and the diagnosis serves as clinical confirmation of atypicality (Rolland, 1984, 1994, 1999). Gradual onset is generally consistent with many families of individuals diagnosed with an ASD's experience with the diagnostic process. The literature related to families of individuals diagnosed with an ASD notes that the majority of these families have experienced the diagnostic process as a confirmation of their previous suspicions of atypicality (Gray, 1995; Marcus, Kunce, & Schopler, 2005). It should be noted, though, that some families have reported an acute onset in which the child's ability to produce language and relational qualities quickly regress. Thus, it is important to ascertain the family's relative experience with the onset of the ASD.

Level of uncertainty, another aspect of the psychosocial typology of illness, is defined as the predictability of a particular illness or disability and can be considered a "metacharacteristic that overlays and colors the other attributes: onset, course, outcome, and incapacitation of any disorder" (Rolland, 1994, pp. 33). The less certain the course and outcome of an illness, the more strategic and flexible a family needs to be regarding problem solving and planning, often exhausting even the most resilient and adaptive families (Rolland, 1994, 1999). Uncertainty is conceptualized as a multidimensional

concept that arises from many aspects associated with a particular illness or disease (Cohen, 1993; Mishel, 1988, 1999, Rolland, 1994). Several authors have suggested that uncertainty regarding a chronic illness or disability can increase family distress and, as that uncertainty becomes prolonged, disrupt family functioning (Boss, 1999; Cohen, 1993; Patterson & Garwick, 1994; Rolland, 1994, 1999; Sharkey, 1995). Given the level of uncertainty present in the etiology of ASDs, their course, and level of incapacitation over time, the experience of uncertainty by families of individuals diagnosed with an ASD is particularly relevant when conceptualizing the impact ASDs have upon families.

Course of an illness or disability is the trajectory or path that an illness or disability will take over time. It is characterized as being progressive, constant, or relapsing/episodic (Rolland, 1994, 1999). Progressive refers to a chronic state that, over time, is continually symptomatic and increases in severity either rapidly or slowly (Rolland, 1994, 1999). Constant refers to a chronic state that, once developed, poses a clear, stable, and predictable deficit over a defined period of time (Rolland, 1994, 1999). A relapsing/episodic course tends to alternate between periods in which the individual displays low levels of symptoms or is asymptomatic with periods of exacerbation (Rolland, 1994, 1999). With respect to ASDs, the course of this particular disorder also may have significant implications for the family system. That is, since the long term level of incapacitation for an individual diagnosed with an ASD is unpredictable, different families may experience the course of their family member's ASD in different ways.

The category of *outcome* focuses on the degree to which an illness or disability can shorten an individual's life or result in death (Rolland, 1994). With respect to ASDs,

there is some evidence that two of the disorders, namely Rhett's syndrome and Childhood Disintegrative Disorder, do impact an individual's life expectancy (Van Acker, Loncola, & Van Acker, 2005; Volkmar, Koenig, & State, 2005). While there is no known impact upon life expectancy for the other ASD classifications (i.e., PDD-NOS, Autism, or Asperger's Disorder), ASDs in general are often comorbid with other neurological (e.g., epilepsy), behavioral (e.g., self-injurious behavior), and medical conditions (e.g., Fragile X, Mitochondrial disorders) that have unclear long-term impacts upon life expectancy and/or quality of life (Minshew, Sweeney, Bauman, & Webb, 2005; Van Acker, Loncola, & Van Acker, 2005; Volkmar & Klin, 2005).

Some authors have also expanded this category to include ambiguous loss and grief felt by many families for the loss or death of their "idealized child" (Boss, 2007; O'Brien, 2007). Typically, parents hold hopes, dreams, and fantasies regarding their children that slowly change over time to incorporate the child's own self-developed hopes and dreams. However, in families of individuals diagnosed with a chronic illness or disability, including ASDs, parents' dreams for their child's future are challenged early and abruptly, often dissolving into views of an uncertain future (O'Brien, 2007).

Finally, *incapacitation* refers to the extent to which an illness or disability involves impairment of an individual's level of cognition, sensation, movement, stamina, as well as the degree to which an individual is disfigured or experiences social stigma (Rolland, 1984, 1994, 1999). Rolland (1999) noted that the extent to which an individual is incapacitated, as well as the kind of incapacitation, will impact the degree of family stress. In addition, Rolland (1994, 1999) notes that multiple domains of deficits in the

individual will necessitate a greater level of change within the family system. The impact of the level of incapacitation of the individual will depend not only on the type and severity of impairment(s), but also on the family's structure, flexibility, emotional resources, and financial resources (Rolland, 1994, 1999).

When considering ASDs, the level of incapacitation of an individual can be dependent upon several factors. First, as a 'spectrum' disorder, individuals with the same diagnosis can display varying levels of difficulty in diagnostic-specific areas, i.e., communication, social interaction, and patterns of behavior, interests, and/or activities (Coplan, 2003; National Research Council, 2001). Beyond impairments in diagnostic specific areas, individuals diagnosed with an ASD often have associated medical and behavioral issues that influence the degree to which the individual is impaired. For example, individuals with ASDs often present with medical issues such as hyperacusis (i.e., auditory sensitivity), issues with diet (e.g., low levels of food acceptance, high levels of food selectivity by type and texture), gastrointestinal complaints, and sleep disturbances (Filipek, 2005). Level of incapacitation may also be influenced by the degree to which an ASD individual displays associated behavioral issues (e.g., hyperactivity, obsessive-compulsive behaviors, aggression, stereotypy, and affective symptoms) and neuropsychological issues (e.g., impairments in attention, memory, and cognitive functioning) (Tsatsanis, 2005; Volkmar & Klin, 2005).

Rolland suggests that beyond these five categories, other general aspects of a chronic health condition can have significant implications for an individual and family's adaptation. For instance, the invisibility of a disease, or the lack of visible markers, can

increase the level of denial a family has about the disease and their tendency to minimize its impact (Rolland, 1994, 1999). This aspect can be particularly important in families of individuals diagnosed with an ASD, given the "normal" (i.e., non-stigmatizing physical attributes) physical appearance of many individuals diagnosed with an ASD. Combined with the appearance of normalcy, the range of strengths of some individuals diagnosed with an ASD, from advanced levels of viso-spatial, musical, or academic abilities, may also complicate or cloud families' understanding of the individual diagnosed with ASD's areas of weakness and variable functioning. Given the individual diagnosed with an ASD's outward appearance of normalcy, community members who witness that individual having functional or behavioral issues may not attribute these occurrences to the disorder, but rather to character flaws of the individual or to bad parenting. Thus, the level of invisibility of the individual's ASD, how a family defines the causes of the individual diagnosed with an ASD's presentation and functioning (i.e., symptom expression of disorder, willful intent, etc.), and the family's experiences of acceptance or rejection within the community could also be important areas to assess for overall intervention implications.

In families of ASD individuals, the psychosocial typology of illness helps provide a base from which to understand disability-related factors that may be of particular importance with this population, as well as a frame to understand universal illness/disability-related concerns that families often face regardless of the type of condition. Interacting with the psychosocial typology of illness are family variables that influence outcomes, particularly the belief systems that individuals and families naturally

develop that provide a map to help guide disability-related decisions and shape health-related behavior (Rolland, 1994, 1999). In assessing families' health-related beliefs, Rolland (1994, 1998) proposed several areas or domains that practitioners should examine. A full discussion of all of these areas is beyond the scope of this study (please see Rolland, 1994, for full description). However, several areas may be domains of note with respect to families of ASD individuals. These include the family's optimistic/pessimistic beliefs, the family's mastery beliefs, and their views regarding control over the health condition.

Optimism and Reality. A key belief system that influences how a family responds and adapts to a specific health condition is the extent to which a family is optimistic regarding their life in general and/or the specific health condition they face. Optimism and hope are considered important aspects of family resilience (Walsh, 2002, 2003). As such, Rolland suggests that practitioners should assess the extent to which families hold positive beliefs about their future, beliefs about the impact of the chronic condition, and the extent to which they accept or minimize the realities associated with a particular chronic condition (Rolland, 1994, 1999). Given the chronicity and potential needs and complications associated with specific illnesses or disabilities across the individual's lifespan, the family needs to maintain a balance of hope or optimism and reality within the family system. This balance is considered to be particularly necessary in conditions, like ASDs, that have both uncertain courses as well as strenuous treatments (Rolland, 1994). To function optimally, families in these situations may need to acknowledge the condition and its many aspects, minimize the potential for poor outcomes, and maintain

positive hopes and dreams (Rolland, 1994, 1999). As Rolland (1994) notes, most individuals could not tolerate continued focus on the realities of a particular condition. Thus, hope and optimism are thought to help facilitate action and productive thinking about a condition in a way that is manageable to a specific family (Rolland, 1994, 1999). Other researchers support this view and note that beliefs regarding optimism about the future often helps reduce individuals' and families' fears of uncertainty and loss and increase their well-being (Robbins & Kliewer, 2000; Scheier and Carver, 1992; Taylor, 1989).

The use of hope and optimism by families is different from practicing denial. For example, those who are optimistic about a health condition acknowledge the presence of a condition, while those in denial do not, or assign different labels or meanings to a condition. Denial of a condition tends to lead to inaction or action based on potentially superficial understanding of treatment aspects and risks (Rolland, 1994, 1999). When a family discounts the presence of a condition or its severity, there exists little motivation for the family to institute individual and family-level change. If a family is unable to discuss treatment aspects and risks, or avoids acknowledging a condition, the family may engage in treatments or procedures without an informed understanding of the risks and benefits of that treatment (Rolland, 1994, 1999).

Mastery & Control. Rolland (1994, 1998, 1999) notes that, along with families' optimistic beliefs, it is also important to understand how families construct a definition of mastery and control regarding general and health-specific situations. Within the chronic illness and disability literature, much attention has been given to individual's and family's

beliefs regarding mastery and control. These two beliefs are considered to be separate, but equally important. Mastery typically involves beliefs that life events are manageable or comprehensible (Antonovsky, 1987; Antonovsky & Sourani, 1988), while control involves the extent to which one can control life events, including disability or illness (Dohrenwend & Dohrenwend, 1981; Levenson, 1973).

Not surprisingly, a family's beliefs regarding mastery and control often overlap with their sense of optimism and hope. Families who have a greater sense of mastery or control over adversity will often endorse beliefs of hope and optimism that extend beyond the biological aspects and outcomes of the family member's condition to include family beliefs regarding quality of life and the family's overall identity (Rolland, 1994, 1999). Conversely, families who believe they are less competent and have less control over a condition will prescribe greater importance to the biological outcomes of an illness, thus gaining and losing hope dependent upon the biological course of the condition (Rolland, 1994, 1999).

Convergence of Theories

While a growing body of literature has focused on families of ASD individuals, this body of work does not often note the theoretical framework which the authors use to organize their findings. Such theoretical frameworks are needed in order to contextualize and best utilize the current research findings on families of individuals diagnosed with an ASD, as well as identify areas that demand further attention. As such, both the FAAR model and the Family Systems-Illness Model may prove useful. At its heart, the FAAR

model provides a general scheme from which to understand: 1) the general factors associated with facilitating optimal adaptation in families facing a crisis, and 2) the relationships between family demands, family capabilities, and family beliefs which influence family adaptation. While congruent with the FAAR model in several areas, the Family Systems-Illness Model additionally provides guidance regarding specific factors that either promote or hinder family adaptation to a family member's chronic health condition. These include disability-specific factors and particular family beliefs that can directly and indirectly influence an individual's and family's adaptation to a health condition.

Three main aspects of the FAAR model and the Family Systems-Illness Model are compatible, if not overlapping, and have important implications for work with families of individuals diagnosed with an ASD. First, promoting the overall positive adaptation of both the individual diagnosed with an ASD and his/her family necessitates examining both the demands and capabilities of these families. While previous research on families of individuals diagnosed with an ASD can be categorized as research regarding specific demands (or deficits) or capabilities (or strengths) of these families, relatively little of this research has specifically focused on the health-related aspects highlighted by Rolland's psychosocial typology of illness, particularly the level of incapacitation and the level of uncertainty related to an individual's ASD.

Second, as both models have noted, family beliefs are vitally important factors that are thought to have significant influence upon both the family's perception and management of their capabilities and demands as well as their overall adaptation and

resilience (King et al., 2006; McCubbin & McCubbin, 1993; Hawley, & DeHaan, 1996; Walsh, 1998). These beliefs, particularly the extent to which a family holds optimistic beliefs, mastery beliefs, and control beliefs regarding an individual's ASD, and their direct relationship with either individual or family related outcomes have also received little attention within the ASD literature.

In addition, the extent to which family members' beliefs act as mechanisms through which demands and capabilities influence adaptation has also received little attention in the ASD literature. As noted previously, the FAAR model posits that family beliefs can be either mediators, moderators, or function as both (Patterson, 2005). The literature on general well-being typically notes that the distinction between mediator and moderator status depends upon how the variables are conceptualized and assessed (Robbins & Klewier, 2000). For this study, optimism, mastery, and control beliefs are conceptualized as mediators, or the mechanisms through which uncertainty and level of severity influence adaptation, rather than as moderators, or variables that affect the direction or strength of the relationship between variables (Baron & Kenny, 1986; Robbins & Klewier, 2000). Defining family beliefs as mediators is congruent with this study's underlying conceptualization of these variables as ways in which individuals construct meaning in their lives. Thus, people who report low levels of uncertainty and lower levels of perceived severity report greater levels of positive adaptation because they are more optimistic, have more feelings of mastery, and a greater sense of personal control. This mediational definition is congruent with the conceptualization of these

beliefs as the lenses through which families construe their health related experiences (Rolland, 1994).

Finally, while a growing body of research has focused on positive individual outcomes of families of individuals diagnosed with an ASD, relatively little research has focused on family-level outcomes or positive family adaptation. Within a family resilience and systems framework, adaptation broadens from indicators of positive individual functioning to also include family level functioning. Thus, the adaptation of the family necessitates looking beyond the reduction of negative outcomes in individual family members and towards the promotion of positive family outcomes, such as family quality of life.

As noted in Chapter 1, this current study proposes that the impact of the specific health-related demands of uncertainty and level of perceived severity of an individual's ASD on the family's overall adaptation will be mediated by family members' level of optimism and beliefs regarding mastery and control. To understand the current literature on which this study's hypotheses are based, the following sections will first classify variables with respect to the FAAR model's designation of capabilities/demands, family beliefs, and family adaptation. Then each section will define these variables and review the existing literature of the specified variables in families of individuals diagnosed with an ASD. Given the paucity of existing research of many of these variables with respect to families of individuals diagnosed with an ASD, these sections will also review the existing research related to these variables derived from the literature on families of chronically ill or disabled individuals, a broader general category. Finally, the following

sections will also designate how this study proposes to expand upon the current knowledge base of families of ASD individuals.

Capabilities and Demands

A growing body of literature has examined elements that either support positive outcomes or lead to negative outcomes in families of individuals diagnosed with an ASD. Not surprisingly, much of this research can be categorized into the family resilience classifications of capabilities/strengths or demands/risks. This study selected two areas consistent with Rolland's (1994) psychosocial typology of illness to represent specific risk/demand factors. These two factors are the uncertainty regarding the child's ASD diagnosis and the parents' perception of the individual diagnosed with an ASD's level of severity. Therefore, this section will define these two constructs, the rationale for their selection, the current literature on the specified construct in both the ASD and broader chronic illness and disability literature, as well as gaps in the literature on which this study looks to provide further information.

Uncertainty

As noted within the Family Systems-Illness Model's psychosocial typology of illness (Rolland, 1994, 1999), uncertainty is a construct considered to have significant impact upon the type of tasks faced by families as well as families' experience with a particular disability or illness. Within the chronic illness and disability literature, uncertainty has been defined as the inability to predict what will happen, what the consequences of an illness-related event or diagnosis are, and what the illness-related

event or diagnosis means (Mishel, 1988). Uncertainty often occurs when a person does not have enough information to adequately structure or understand a particular health-related event, resulting in a state of heightened sense of vulnerability and need to know the unknowable future (Cohen & Martinson, 1988; Mishel, 1988).

While a great deal of the health-related literature has examined the impact of uncertainty upon individuals faced with chronic and acute health conditions, less research has focused on the impact uncertainty has upon caretaker or family functioning. What literature exists, however, provides rich descriptive examples of the way in which uncertainty can impact family members' lives. For example, Cohen (1993, 1995) notes that, while uncertainty is a unidimensional concept until the child's symptoms are given a unifying label or diagnosis, after the diagnosis uncertainty becomes a multidimensional construct encompassing six dimensions: existential, etiologic, treatment, situational, biographical, and social uncertainties (Cohen 1993, 1995). As she notes:

> Parents must acquire new parenting behaviors that are not shared by their contemporaries, deeply ingrained beliefs are proven wrong, long-held values undergo major changes or are rendered inapplicable, and expectations for the future can no longer be taken for granted. The diagnosis creates a biographical reality for these parents that sets them apart from others in their world. The diagnosis becomes an assault on previously held knowledge, beliefs, expectations, and values… The diagnosis defies any sense of logic or justice or fairness. The taken-for-granted world abruptly ceases to exist. (Cohen, 1993, pp. 82-83).

The diagnostic process typically provides a concrete answer to the question 'what is wrong with my child,' but produces multiple additional unanswerable questions and a variety of emotional states (Cohen, 1993).

Across the family's lifespan, uncertainty is thought to continue to exist in a sustained manner. As a disability's or illness' symptoms become more predictable and

the family becomes better adjusted to their new reality, uncertainty is thought to take on a wave-like pattern of existence, in which it remains at tolerable levels until a major stressor or event arises, at which time uncertainty peaks and becomes distressful (Cohen, 1993). Family members naturally learn over time how to manage their varying levels of uncertainty by developing strategies to manipulate the known, the unknowable, and the unknown, all in order to reduce stress and develop healthy adaptation to their situation (Cohen, 1993).

This description of uncertainty, while developed for families faced with acute and chronic illness and disabilities, captures the essence of the experiences faced by families of individuals diagnosed with an ASD. No two children diagnosed with an autism spectrum disorder demonstrate the same pattern of symptoms and areas of strengths (Coplan, 2003). Likewise, the outcomes for individuals diagnosed with an ASD are equally variable (Howlin, Goode, Hutton, & Rutter, 2004). Similar to the developmental psychopathology concept of multifinality (Cicchetti & Rogosch, 1996), or similar states leading to varied outcomes, children diagnosed with an ASD who appear similarly impaired as children may have very different functional and adaptational outcomes as adults. For example, some individuals diagnosed with an ASD who appeared severely impaired as children are able to work and live with minimal support as adults, while others need intensive support and intervention into adulthood (O'Brien, 2007). Thus, families of individuals diagnosed with an ASD are faced with uncertain courses, varying predictability of symptom expression, and no clear paths that produce specific, predictable long-term outcomes.

Families of individuals diagnosed with an ASD additionally face etiological and treatment uncertainties. For instance, there currently is no consensus on what causes autism spectrum disorders. Similar to the developmental psychopathology concept of equifinality (Cicchetti & Rogosch, 1996), or different pathways leading to the same outcome, current research in ASDs continue to implicate a variety of genetic, neurobiological, and environmental aspects in the expression of autistic-like symptoms or that correlate with ASD diagnoses (e.g., Anderson & Hoshino, 2005; Rutter, 2005; Filipek, 2005). Given the etiological uncertainty of ASDs, debate exists in the general media regarding whether ASDs are disabilities or illnesses. Underlying this distinction is the notion of "cure." That is, if an ASD is a disability, energy should then be spent toward adapting to that disability, which will always be present. Conversely, if ASDs are illnesses, a "cure" for ASDs could be found, thus providing hope for a full recovery to a typically-developing state.

Compounding the existing etiological uncertainties of ASDs are the uncertainties regarding appropriate treatment. In general, there exists a great deal of research regarding different medical, behavioral, and education treatments, but this research base has tended to have methodological flaws (e.g., minimal demographic information on the population of study, insufficient detail of treatment intervention, examining effects of treatment vs. non-treatment specific factors such as intensity or personnel characteristics, etc.) and remain unintegrated across bodies of literature or disciplines (National Research Council, 2001). These areas of need within the literature on ASD treatment could arguably create a situation in which parents may not be well informed regarding

treatment choices, or how to effectively choose appropriate treatments for their child. These etiological and treatment uncertainties thus could influence parents' interactions with their child, with practitioners, and even influence their selection of treatment. For example, parents often hear or read about alternative therapies that are marketed as being able to not only reduce symptoms or promote strengths, but "cure" autistic children of their disabling condition. Thus, many families often utilize a wide range of treatments that have varying levels of empirical support and potential negative medical side effects.

While Cohen (1993, 1995) and Mishel's (1984, 1988) conceptualization of uncertainty in families of chronically ill and/or disabled children fits well with the experiences of families of children diagnosed with an ASD, surprisingly no quantitative studies examining the impact of uncertainty with this population could be found. Lack of certainty and clarity regarding outcomes for family members diagnosed with an ASD have, however, emerged in narrative themes in qualitative studies of this population (e.g., O'Brien, 2007; Gray, 2002). For example, in a mixed-method study of 63 mothers of children diagnosed with an ASD, O'Brien noted that narratives often included themes of confusion and uncertainty about the child diagnosed with an ASD and mother's future as well as managing the uncertainty associated with daily changes in the child's functioning (O'Brien, 2007). In this study, mothers also noted difficulty in knowing what level of functioning to expect from their child, particularly when their child displayed varying level of skill in different areas (O'Brien, 2007). In addition, many mothers noted an overall sense of being "constantly off-balance" and having a lack of clarity regarding eventual outcomes for their children (O'Brien, 2007).

Similar themes of uncertainty are also reflected in other qualitative studies of families of individuals diagnosed with an ASD. For example, in a qualitative longitudinal study involving 28 parents of individuals diagnosed with an ASD, Gray (2002) noted that participants' narratives included themes of uncertainty and anxiety regarding their child's future. In addition, some participants also noted uncertainty arising from the unpredictability of their child's aggression. While these themes were consistent with those of parents of younger individuals (Gray, 1994), fears regarding the uncertainty of the child's future and the inconsistent expression of aggression reportedly increased as the child aged (Gray, 2002). These fears, particularly regarding the level of dependency and future outcomes of children diagnosed with an ASD, are reflected elsewhere in the literature (e.g., Holroyd & McArthur, 1976, Sanders & Morgan, 1997).

Within the literature on families of individuals diagnosed with a chronic illness or disability, some quantitative and qualitative studies have examined the impact of uncertainty upon family members, particularly parents. Sanders-Dewey, Mullins, and Chaney (2001) examined the impact of uncertainty in 44 caretakers of adult partners diagnosed with Parkinson's disease. The study found that perceived uncertainty emerged as significant predictors of distress in caretakers (Sanders-Dewey, Mullins, & Chaney, 2001). Similarly, Jessop and Stein (1985), in a study of 209 mothers of chronically ill or disabled children, also found that these mothers reported more psychological distress when faced with increased uncertainty. These studies note that the most common consequence of sustained uncertainty is psychological distress in parents. Whether the distress measures are defined as anxiety, depression, stress, or helplessness, these studies,

and others focusing on adults with chronic conditions, note a relationship between individual distress and uncertainty (Grootenhuis & Last, 1997a, 1997b; McNulty, Livneh, & Wilson, 2004; Miles, Funk, & Kasper, 1992; Mishel, 1984; Schepp, 1991).

Uncertainty associated to symptom expression has also been examined within the literature on families of chronically ill or disabled children. In a study that included 173 mothers and 150 fathers of children with a variety of chronic conditions, Dodgson and colleagues (2000) noted that the unpredictability of a child's symptoms was significantly associated with greater family and social disruption for both mothers and fathers, and increased emotional strain and financial burden for mothers. The authors concluded that parents of young children with intermittently unpredictable symptoms were at a greater risk for negative outcomes than families in which their child's symptoms were more predictable (Dodgson et al., 2000).

Likewise, in a study that included 99 mothers and 86 fathers of children with a variety of chronic conditions, unpredictability of symptoms were also generally found to be associated with an increased level of family distress (Garwick et al., 2002). Specifically, Garwick and her colleagues noted that unpredictability of symptoms were significantly associated with greater levels of emotional strain for mothers and greater levels of family social disruption for fathers (Garwick et al., 2002). These authors also noted that the child's stage of development influenced the extent to which the degree of uncertainty of that child's illness or disability impacted the family, with families of older children having found ways to incorporate the chronic condition into their life (Garwick et al., 2002).

Collectively, this body of literature supports the view of uncertainty as a significant source of stress and distress in families of individuals diagnosed with a special need such as ASD (Rolland, 1994). Surprisingly, although the impact of uncertainty conceptually fits well with the experience of families of individuals diagnosed with an ASD, almost no literature exists examining its role in either individual or family level outcomes. What literature that does exist with regards to this population has examined the role of uncertainty using qualitative methodology. Therefore, the current study looks to provide quantitative information regarding the impact of uncertainty on families of individuals diagnosed with an ASD. Since past related research in the chronic illness and disability literature have noted a relationship between parental distress and uncertainty, this study will look beyond the individual outcomes previously reported to examine outcomes associated with the family as a unit. Specifically, this study will examine the extent to which uncertainty predicts family quality of life, an indicator of family adaptation to chronic illness or disability.

As theorized by the FAAR model, uncertainty can be defined as a family demand, both as an initial stressor (i.e., at time of diagnosis) and as an ongoing strain (e.g., variability in symptom expression, uncertain future, etc.). As such, the impact uncertainty has upon family adaptation could be influenced by family members' beliefs. To date, no literature has examined the relationship between uncertainty, beliefs, and adaptation within the literature on families of individuals diagnosed with an ASD. Some support for this hypothesis does exist, however, within the chronic illness and disabilities literature. Specifically, having positive expectations and using strategies to implement

control have been found to reduce levels of uncertainty in parents of children with cancer (Grootenhuis & Last, 1997b), while beliefs regarding mastery have been shown to mediate the influence level of uncertainty has on perceptions of danger in women diagnosed with cancer (Mishel, Padilla, Grant, & Sorenson, 1991). This study will examine the extent to which the impact that uncertainty has on family adaptation is mediated by the beliefs parents hold regarding ASD and their experience with ASD.

Severity

In addition to the impact of uncertainty, the level of incapacitation, or level of severity, of a child's ASD diagnosis could also have a significant impact upon the family's functioning and adaptation (Rolland, 1994, 1999). Severity or incapacitation can have a variety of definitions, but has been broadly defined by Rolland as the extent to which there are functional limitations and/or social stigmata associated with a particular illness or disability (Rolland, 1994, 1999). Several individuals have suggested that, as a child's level of incapacitation or severity of impairments increase, so does parental and familial levels of stress (e.g., Folkman, Schaefer, & Lazarus, 1979; Rolland, 1994, 1999). Given this hypothesized relationship, one can argue that the level of severity of a particular illness or disease is congruent with the FAAR model's definition of a family demand, particularly as an on-going strain upon the family. Therefore, understanding the relationship between level of severity of an illness or disease and outcome indicators, such as family adaptation, as well as aspects that influence the level of severity's impact, could have significant importance on effective intervention strategies with families of ASD individuals.

Unlike uncertainty, level of severity of a child's ASD or developmental delay symptomatology has received a good deal of attention within the literature, either as a primary focus of a particular study or as a variable included within a study's larger focus. While most studies have noted a positive relationship between the level of severity of the child diagnosed with an ASD or developmental delay's symptoms and parental distress, some divergent findings have been noted within the broader literature on chronic illness and developmental disabilities. For example, three studies found no relationship between the level of severity of the symptoms of the child diagnosed with a developmental disability and parental levels of distress (Jones & Passey, 2005; Skok, Harvey, & Reddihough, 2006; Trute & Hauch, 1988). This inconsistency with the bulk of the literature on severity and family stress may be the result of the broad range in definitions that studies have used to define and measure severity in chronic health conditions, including ASDs.

For example, in the studies which found no relationship between level of severity and parental distress, "severity" was defined as either gross motor functioning (Skok, Harvey, & Reddihough, 2006), an undisclosed 53 item "behavioral checklist" (Jones & Passey, 2005), and a 4 item "Disability Index" (Trute & Hauch, 1988) created specifically for their study. In contrast, other studies have measured severity using standardized behavioral measures, including autism-specific behavior checklists (e.g., adapted CARS, ABC), general adaptive behavior scales (e.g., Vineland, Child Behavior Checklist), conduct behavioral problem scales (e.g., Eyberg Child Behavior Inventory), or chronic illness/disability scales (e.g., Characteristics of Chronic Conditions measure).

These scales have measured severity as deficits in either autism-specific criteria, general deficits in functional skills, or behavioral difficulties consistent with conduct issues. Thus, a great variability in definitions of 'ASD severity' or 'chronic illness/disability severity' have been utilized within the literature.

In an attempt to synthesize the data on severity of ASD and its impact upon the family, it is most useful to categorize outcomes not by the general category of "severity," but with respect to similarities across studies and specific domains of functioning. For example, studies that have focused on ASD 'severity' have defined severity as deficits in a variety of areas, including motor delays, social skill deficits, communication deficits, adaptive living skill deficits, antisocial behaviors towards others, etc. When looking for unifying themes, however, several important findings arise.

First, the majority of research on family or parental distress and ASD severity indicates that the more severe a child's ASD, the greater the parental distress. Specifically, several outcomes have been associated with the level of severity of an individual's ASD, including maternal stress (Donovan, 1988; Hanson & Hanline, 1990; Hassall, Rose, & McDonald, 2005; McKinney & Peterson, 1987; Plant & Sanders, 2007; Seltzer & Krauss, 1989), maternal depressive symptoms and marital dissatisfaction (Berge, Patterson, & Rueter, 2006). However, some studies have not found an association between severity of the child's ASD or developmental delay and parental depression (e.g., Bristol, 1987b; Trute & Hauch, 1988). Some authors have suggested that the discrepancies found within this literature may be the result of how parental distress is defined. Specifically, studies typically agree that parents of ASD children

experience more stress, but may not meet the criteria for clinical depression, a commonly utilized outcome variable (Bristol & Schopler, 1984).

Second, children diagnosed with an ASD typically are categorized as having more "severe" symptomology and contributing to greater levels of parental distress than many other types of disabilities. In a study comparing families of children diagnosed with an ASD, Down syndrome, a behavior disorder, and typically developing children, Dumas and colleagues (Dumas, Wolf, Fisman, & Culligan, 1991) noted that both mothers and fathers of children diagnosed with either an ASD or a behavioral disorder experienced greater levels of stress and depressive symptoms as compared to the Down syndrome and typically developing groups. Given the similar patterns in the results of this study between families of children diagnosed with an ASD and families of children diagnosed with behavioral problems, the authors suggested that it was the presence of these behavioral problems which heighten parents' assessment of their child's severity.

In addition, families who report their child diagnosed with an ASD as more severe typically report that these children have greater difficulties in behavioral areas than other ASD peers. For example, in a study by Konstantareas and Homatidis (1989) of 44 parents of autistic children, parents assessed their children as more symptomatic, and more severe, if they were hyperirritable, odd-looking (i.e., bizarre use of body, stereotypy), or self-abusive. Within this study, the authors noted that the best predictor of parental stress was self-abusive behavior. Mothers' level of stress was also predicted by hyperirritability (i.e., extremely difficult temperament, unsafe behaviors such as running, and aggressive behaviors) (Konstantareas & Homatidis, 1989). Similarly, Dumas and

colleagues noted that parents' reporting of severity of an ASD child's condition was significantly related to the level of intensity of the child's conduct behavioral problems (Dumas, Wolf, Fisman, & Culligan, 1991). Several other studies have noted that increased level of parenting burden, depressive symptoms, and stress (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Berge, Patterson, & Rueter, 2006; Donenberg & Baker, 1993; Essex, Seltzer, & Krauss, 1999; Hastings, 2003; Herring et al., 2006; Tonge & Einfeld, 2003), as well as decreased levels of marital satisfaction and family quality of life (Wang et al., 2004) are noted when emotional or behavioral problems are comorbid with a developmental disability or chronic illness/disability with functional deficits.

Finally, some evidence also suggests that when severity is defined along ASD diagnostic criteria, the greater the deficits in these domains, the greater the level of stress within the family. For example, when children display lower levels of communication skills and/or lower cognitive functioning, higher levels of family stress are also present (Frey, Greenberg, & Fewell, 1989; Konstantareas & Homatidis, 1989).

As these findings suggest, discrepant findings within the ASD, chronic illness and developmental disability literature may be influenced by the way "severity" is defined within a given study. Aspects both specific to the diagnosis of an ASD (e.g., communication difficulties) and associated factors (e.g., behavioral issues such as aggression and self-injurious behaviors) may 'pile-up' to increase the perception of severity. For some family members, severity of ASD diagnostic-specific domains may not be as incapacitating as other related issues, such as self-injurious behaviors or aggression. As noted in one study, families with a child that has no mobility or verbal

skills may be less challenging than a child who is highly verbal or mobile but displays a significant amount of aggressive or other problem behaviors (Wang et al., 2004). Thus, it is important to include both ASD-specific and other related factors when assessing families of individuals' diagnosed with an ASD's perception of severity. Congruent with this position, this study will examine family's reported level of severity by utilizing a measure that incorporates both ASD-specific diagnostic issues as well as those broader aspects that can be common complaints of families of ASD individuals (e.g., aggression towards self or others, sleep issues, etc.).

In addition, while a great deal of research has examined the individual outcomes associated with level of severity, relatively little attention has been given to the impact level of severity may have upon a family-level outcomes. In the review of the literature on families of individuals diagnosed with an ASD, no studies were found that utilized family-level outcome measures such as family adaptation. Within the literature on chronic illness and disability, only one study was found that examined the impact of severity upon family quality of life, an indicator of family adaptation. In this study, Wang and colleagues found both mothers and fathers indicate that the severity of a disability is a significant predictor of the family's quality of life (Wang et al., 2004). Therefore, this current study looks to expand the literature on the impact severity has within families of children diagnosed with an ASD by examining the relationship between perceived level of severity and the family's overall adaptation.

Finally, discrepancies within the literature with respect to the impact ASD has upon parents or families may also reflect factors that influence the relative impact of

severity upon selected outcomes. As proposed by the FAAR model, family beliefs are thought to act as mediators or moderators of various stressors upon the family's adaptation to a chronic illness or disability (Patterson, 2005). A literature review was unable to find any studies of families of ASD individuals that examined potential mediators of the relationship between severity and individual or family outcomes. Within the chronic illness and disability literature, few studies have examined factors that potentially mediate the influence of severity. Those that have (e.g., Baker, Blacher, & Olsson, 2005; Saloviita, Italinna, & Leinonen, 2003; Plant & Sanders, 2007) have suggested that the meaning or attributions made by parents can mediate the effects of severity. Therefore, this study will also examine the extent to which family beliefs mediate the impact perceived severity has upon family adaptation. Further details regarding this proposed relationship will be reviewed in the following section outlining family beliefs.

Family Beliefs

As both the FAAR model (Patterson, 1988, 2002, 2005; Patterson & Garwick, 1994) and the Family Systems-Illness Model (Rolland, 1984, 1987, 1994, 1999, 2003) suggest, the beliefs that family members hold about a family member's illness or disability-related condition are vitally important factors that can directly and indirectly impact the adaptation, coping, and resilience of families (Hawley, & DeHaan, 1996; Lazarus & Folkman,1984; McCubbin & McCubbin, 1993; Roland, 1994; Walsh, 1998). As Rolland (1994, 1999) notes, families' level of optimism, mastery beliefs, and control

beliefs may be particularly important areas to assess in families faced with chronic conditions. This is supported in the counseling psychology literature, where beliefs, such as optimism and mastery, have been shown to play important roles in the areas of well-being and health promotion (Hoffman & Driscoll, 2000; Robbins & Kliewer, 2000).

Thus, this study suggests that family beliefs, particularly those of parents or primary caregivers, have both direct and indirect influence on how a family adapts to their family member's ASD. Specific family beliefs, those of optimism, control, and mastery, are the focus of this study. These beliefs are the primary focus of this study given their theoretical importance, as well as the importance placed upon them within the broader literature on chronic illness and disability. Therefore, this section will define the specific belief constructs of inquiry in this study, the rationale for their selection, the current literature on the specified construct in both the ASD and broader chronic illness and disability literature, as well as gaps in the literature which this current study hopes to address.

Optimism

As noted by Rolland (e.g., 1984, 1994, 1999), the balance between realistic expectations and hopes for the individual with a chronic illness or disability is important in facilitating optimal functioning and adaptation in the family. Optimism has received a good deal of attention within the positive psychology and health/rehabilitation psychology literature. Having conceptual roots within expectancy-value models of motivation, optimism has been defined as the expectation of good outcomes (Carver & Scheier, 2003). Reflecting its motivational roots, people who view life optimistically

believe that good outcomes are contingent upon remaining in pursuit of those good outcomes, whether through active efforts or passively remaining involved and capitalizing on “breaks” or events that fall in their favor (Carver & Scheier, 2003). Thus, optimistic individuals expect optimal outcomes, but also understand that they hold a role in influencing that outcome.

Individuals with more optimistic views on life are thought to have different reactions to adversity than those with a more pessimistic world view. Optimists are thought to accept the reality of an adversity quicker, appear to engage in more active coping strategies, and are less likely to disengage or give up in the face of adversity than pessimists (Carver & Scheier, 2003; Scheier & Carver, 2001; Scheier, Carver, & Bridges, 2001). Thus, optimism may have positive impacts upon people’s actions, beliefs regarding outcomes, and understanding of their personal experiences.

While optimism overlaps with the concepts of control and mastery, differences between these concepts do exist. Control, as measured by locus of control or other such constructs, inherently measures the extent to which an individual has personal agency over a particular outcome. Mastery, as measured by self-efficacy or sense of coherence, includes the concept of being able to manage a particular situation, regardless of one’s control over that situation. It can be argued that optimism, while similar in its goals of expected positive outcomes, represents a broader, more general disposition towards experiences and does not necessitate either personal agency or influence.

While much research has examined the impact an individual’s optimism has upon that individual’s health-related outcomes (see Peterson, 2000 for further review), less

research has focused on the impact of parents' optimism towards their chronically ill or disabled children. In a review of the literature on families of children with chronic illness or disabilities, only one study utilized the specific construct of optimism. This study, conducted by Baker, Blacher, and Olsson (2005), surveyed 214 families of 3 year old children classified as being developmentally delayed, borderline delay, or non-delayed. The authors noted that, in selecting this particular sample, they attempted to minimize the inclusion of children with genetic disorders, as they classified autism, that tend to be linked to high levels of behavioral problems. The study found that optimism had a consistently positive relationship to parent well-being (Baker, Blacher, & Olsson, 2005). In addition, while optimism was found to moderate the relationship between child behavior problems and parental well-being, it was not found to mediate this relationship (Baker, Blacher, & Olsson, 2005).

In addition to directly examining optimism, similar concepts, such as positive appraisals and hope, have been examined in the literature on families of children with chronic illness or disabilities. For example, Trute, Hiebert-Murphy, and Levine (2007) examined positive appraisals in 103 mothers and 55 fathers of 4 year old developmentally delayed children. The study noted that positive appraisals of childhood disability were found to predict early family adjustment and were related to enhanced self-esteem in mothers, while longer-term family adjustment was predicted by the level of parental appraisal of the negative family impact of disability (Trute, Hiebert-Murphy, & Levine, 2007). In a separate qualitative study of families of children with cancer, McCubbin and her colleagues noted that positive changes in how a family appraised a situation (e.g.,

seeing good with bad) were found to be protective factors that helped the family manage the child's cancer (McCubbin et al., 2002). Similarly, Kusar and her colleagues (Kusar, Jevne, & Sobsey, 2003) conducted a qualitative study that examined the role of hope in families of children diagnosed with a developmental disability. A total of 19 families participated in either face to face or internet interviews that utilized a semi-structured interview format. From the narrative analysis, hope was identified as a transformation process that helped parents positively reframe their lives, giving them a sense of strength and meaning (Kusar, Jevne, & Sobsey, 2003).

In reviewing the literature on families of individuals diagnosed with an ASD, several studies were found that focused on the related construct of "positive reframing." For example, in a study of families of children diagnosed with an ASD, Hastings and Johnson (2001) noted that parents who adopted coping strategies that included positive reframing reported less stress. Similarly, positive reframing was found to be associated with lower levels of depression in mothers and fathers of individuals diagnosed with an ASD (Hastings et al., 2005b). Likewise, King and her colleagues noted that families who had adapted well over time to having a family member with Down syndrome or autism held world views that were more positive that had changed significantly to include stronger values, increased understanding of societal issues, and a change in values regarding what was "important" in life (King et al., 2006).

Similar to the literature on families of children with chronic illnesses or disabilities, only one study was found to specifically examine the impact of optimism in families of individuals diagnosed with an ASD. In this study, Greenberg and associates

chose to quantitatively examine the impact dispositional optimism, or a general inclination toward expecting positive events in life, had on families with individuals diagnosed with an ASD and other chronic conditions (Greenberg et al., 2004). This study surveyed 125 mothers of adults with Down Syndrome, 292 mothers of adults with schizophrenia, and 102 mothers of adults with autism on their relationships with their adult child, the presence of depression symptoms, and the mothers' level of optimism. The authors noted that mothers of adults with Down syndrome reported significantly better relationships with their adult children than mothers of adults with schizophrenia or autism (Greenberg et al., 2004). These authors also noted that, while no effect was found with mothers of adults with Down syndrome, mothers of adults with schizophrenia and autism had better psychological well-being when they had a better quality of relationship with their child (Greenberg et al., 2004). Finally, for mothers of adults with either autism or schizophrenia, optimism was found to mediate the effect of relationship quality of psychological well-being (Greenberg et al., 2004).

As this collective body of literature demonstrates, positive appraisals or optimistic beliefs appear to be related to positive impacts in families of special needs children. However, this area of inquiry is still in its infancy with families of individuals diagnosed with an ASD. In addition, the one study that both focused on optimism and used an ASD population (Greenberg et al., 2004) sampled only mothers of adult individuals diagnosed with an ASD. Therefore this study looks to add to the existing literature base by focusing on the impact optimism has in families with children diagnosed with an ASD.

In addition, both studies that have directly examined optimism (i.e., Baker, Blacher, & Olsson, 2005; Greenberg et al., 2004) focused on the impact that optimism had upon individual outcomes, such as parental mental health and well-being indicators (i.e., depression, stress), or parent-child relationship indicators. Lacking in this literature is the impact optimism has upon family-level adaptational outcomes, such as family quality of life. Therefore, this study looks to provide further information regarding this relationship by examining how parents' level of optimism predicts family level adaptation.

Finally, consistent with the FAAR model's theorized relationship between demands/capabilities, beliefs, and adaptation, this study posits that optimism will mediate the relationship between specific demands on the family and the family's adaptation. The related literature is mixed as to whether or not optimism acts as a mediator. For example, Baker, Blacher, and Olsson (2005) found no mediational relationship existed between child behavior problems and parent well-being. Greenberg and colleagues (2004), however, did find that optimism mediated the relationship between the quality of the mother-adult child's relationship and parent well-being. Thus, further analysis of optimism's potential role as a mediator within this population may be beneficial.

Control

An individual's belief about personal control, and the coping strategies that arise from this belief, are influenced by the predictability of life's events and those events' outcomes (Williams & Koocher, 1998), as well as culturally, familially, and historically held views regarding control (Rolland, 1994). When a child is diagnosed with an ASD,

these views of predictability and stability are shaken. While families may retain beliefs about their personal control over other aspects of their life, their views regarding their control over the family member's ASD course and outcome may be uncertain.

Within the family systems literature focused on chronic illness and disability, beliefs regarding one's personal control over health outcomes, or health locus of control, are considered to be an area of particular clinical importance (Rolland, 1994; 1999; Williams & Koocher, 1998). Health locus of control embodies individuals' beliefs regarding their personal influence over the course or outcome of an illness. While health locus of control can be conceptualized in multiple ways, some authors have suggested that three subsets of beliefs regarding the agent of change should be the primary foci (Dohrewend & Dohrenwend, 1981; Levenson, 1981; Wallston, Wallston, & DeVellis, 1978). Individuals with an *internal locus of control* tend to believe that their actions or thoughts can affect the course or outcome of a health condition. Individuals with an *external locus of control* focused on *powerful others* believe that, while their own actions will not influence the course or outcome of a health condition, professionals, God, or other powerful individuals can affect the outcome of a health condition. Finally, individuals with an *external locus of control* focused on *chance* believe that luck or fate alone influence health outcomes.

Beliefs about one's level of control over health conditions have been shown to influence health-related outcomes (please see Shapiro, Schwartz, & Astin, 1996 for a review). Health locus of control can have important influences upon the individual and/or family's response to a health condition as well as the individual's or family's

relationship with providers (Rolland, 1994; Williams & Koocher, 1998). Health locus of control has also been identified as potentially influencing both compliance with treatment and level of participation in treatment (Murphy, Thompson, & Morris, 1997; Rolland, 1994, 1999; Wallston, Wallston, & DeVellis, 1978), though results are mixed (Maddux, Brawley, & Boykin, 1995). Rolland suggests that individuals who believe their disability or illness is the result of chance, and that course, level of incapacity and outcome are random, will tend to have less involved relationships with providers (Rolland, 1987, 1994, 1999). Beliefs in chance have been associated with poor psychological adjustment, including the belief that a health outcome is unpredictable and increased depression (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Lipchik, Milles, & Covington, 1993).

Individuals with an external health locus of control focused on powerful others tend to be compliant with treatment (Wallston, Wallston, Smith, & Dobbins, 1989), though this area of health locus of control has received relatively less attention than internal health locus of control (Mackenbach et al., 2001). Rolland suggests that these individuals may be relatively comfortable with intense professional involvement but may have difficulty if professionals are unavailable or if treatment demands self-directed competency (Rolland, 1987, 1994, 1999). Some authors have noted that individuals with strong beliefs regarding powerful others may have more difficulty if the health condition is incurable (Andrykowski & Brady, 1994; Rolland, 1987).

Finally, individuals with internal health locus of control beliefs generally have better adjustment to an illness or disability (Wallston, Wallston, Smith, & Dobbins, 1989). Internal health locus of control beliefs have been shown to be associated with

health knowledge and attitudes (Cunningham, Lockwood, & Cunningham, 1990), psychological adjustment (Smith, Dobbins, & Wallston, 1991) and health behaviors (Bennett, Moore, Smith, & Murphy, 1994). Internal health locus of control is thought to be related to better health outcomes because of a greater likelihood of using active coping strategies (Robison-Whelen & Bodenheimer, 2004; Wallston & Wallston, 1981). Rolland suggests, however, that individuals high in internal health locus of control may need to be involved in a hands-on manner from the beginning of treatment or, at the minimum, feel as if they have some specific areas or tasks that they control (Rolland, 1994, 1999). If the individual's efforts to control a disability or illness are unsuccessful or unable to be actualized, these beliefs may not be beneficial (Andrykowski & Brady, 1994; Williams & Koocher, 1998).

Within the chronic illness and disability literature, some findings support the importance of internal health locus of control for caregivers of individuals faced with a chronic health condition. Specifically, results suggest that caregivers of individuals with chronic health conditions who have an internal locus of control tend to be less depressed and better adjusted than caregivers with a more external locus of control (Bookwala & Schulz, 1998; Braithwaite, 1996; Miller et al., 1995; Pearlin, Mullan, Semple, & Skaff, 1990). High internal health locus of control in these caretakers has also been associated with increased well-being (Brown, 1993; Thompson & Kyle, 2000).

Other studies focused on families faced with disability or chronic illness have reported similar findings using related measures of locus of control. For example, in a study of 141 mothers of children diagnosed with mental retardation (MR), Friedrich,

Cohen and Wilturner (1988) noted that global locus of control buffered the impact of physical incapacitation. In addition, the authors noted that mothers with a more internal locus of control were less depressed than mothers with a more external locus of control (Friedrich, Cohen, & Wilturner, 1988). Similarly, in a study of parents of children with a wide array of developmental disabilities, Jones and Passey (2005) found that parents who had a greater internal locus of parenting control (i.e., control parents feel they have over a child's behaviors or actions) tended to have lower levels of stress. Hassall, Rose, and McDonald (2005) reported similar findings in a study of 46 mothers of MR children. Specifically, the authors noted that mothers with an external parenting locus of control were more likely to experience higher stress levels. This same study also noted that mothers with higher levels of parenting self-esteem were likely to have a more internal locus of parenting control (Hassall, Rose, & McDonald, 2005).

While these studies have tended to focus on health locus of control as a bipolar construct, with particular focus on internal health locus of control, others have emphasized its multidimensional nature (Levenson, 1981; Wallston & Wallston, 1981; Wong & Sproule, 1984) and have called for further research reflecting this nature (Masters & Wallston, 2005). Several authors have suggested that additive or interactive relationships between different aspects of health locus of control, including internal and powerful others (Affleck & Tennen, 1993; Lachman, 1986; Taylor, Helgeson, Reed, & Skokan, 1991), may provide a better fit with individuals' experiences with health conditions.

One study specifically focusing on parents of children with a chronic condition was found to expressly utilize this multidimensional approach to health locus of control. In this study, which focused on 81 mothers of children diagnosed with cerebral palsy, Green (2004) examined the relationship between health locus of control, social support and caretaker burden. The results of this study supported the view of health locus of control as a multidimensional construct. First, this study found that the impact of chance and internality on social support was both additive and interactive; that is, those participants who scored low on both dimensions reported the least social support, while those who scored high on both or either dimension reported greater social support (Green, 2004). Findings from this study also suggested that belief in chance, in combination with internality, is positively associated with decreased subjective burden (Green, 2004).

While a sizable amount of research on locus of control exists in families and individuals faced with chronic illness or disability, relatively little has focused specifically on families of individuals diagnosed with an ASD. This is surprising given that beliefs regarding personal control over the course and outcome of a family member's ASD could have significant influence over the family's ASD-related experience, the role of the family in the individual diagnosed with an ASD's treatment, as well as various individual or family level outcomes. A review of the literature regarding health locus of control beliefs and ASDs, however, revealed that no studies have examined the impact of health locus of control in families of individuals diagnosed with an ASD. In addition, only two studies were found to have examined the impact of control or control-related constructs on outcomes within this population.

The first examined the impact of general locus of control, rather than health-specific beliefs, upon parental stress in families of individuals diagnosed with ASD. In a study of 58 parents of individuals diagnosed with an ASD, Dunn and colleagues (2001) found that, similar to findings reported in the chronic illness and disability literature, external locus of control in participants corresponded with increased depression and reported social isolation (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). However, the authors also noted that general locus of control did not moderate any relationships between variables examined in the study and parental stress.

The second study examined the impact of hardiness and social support on stress in mothers of children with autism, children diagnosed with MR, and typically developing children (Weiss, 2002). In this study, hardiness was defined as a personal attribute that consists of commitment, challenge, and control (Weiss, 2002). The results of the study noted that mothers who believed that they had a good deal of control over events in their lives reported lower levels of depression than mothers who felt more helpless (Weiss, 2002). The author further noted that coping appeared to be enhanced by perceptions of control, self-efficacy, and a general sense of purpose (Weiss, 2002).

Given the theoretical importance and supporting evidence regarding the influence of control beliefs in managing and successfully adapting to a variety of chronic illnesses or disabilities (e.g., Rolland, 1994, 1998; Williams & Koocher, 1998), further research regarding the impact health locus of control may have in the family's adaptation to a family member's ASD is warranted. While results from previous studies on caretakers of individuals diagnosed with an ASD have noted that general personal control beliefs tend

to be related to more optimal individual outcomes in the caretaker, no studies have specifically examined the impact of health-related control beliefs in this population. Given the uncertainty of this particular disorder, it could be that a caregiver can feel in control of various aspects of his/her life, but have relatively less feelings of control over the course and outcome of their child's ASD. Thus, the current study looks to provide further information regarding the health locus of control beliefs within the specific population of families of individuals diagnosed with an ASD.

In addition, while the studies reviewed above have examined the influence of control beliefs upon individual-level outcomes, particularly individual stress, no studies were found to specifically examine the impact parents' health-related control beliefs may have upon family-level outcomes. Since the family system is vital in caring for and fostering optimal long-term outcomes in the individual diagnosed with an ASD, a greater understanding of the relationship between health related beliefs and family outcomes in families of individuals diagnosed with an ASD is needed. Thus, this study will examine the impact parental health locus of control beliefs have upon family-level outcomes.

Finally, while the studies reviewed above have examined the direct relationship between different types of control beliefs and a specified outcome, less research exists regarding the indirect influence caregivers' control beliefs could have with a variety of outcomes. Dunn and colleagues (2001) examined the potential moderating effects general locus of control, social support, and different coping styles have on the relationship between stress and specific outcomes (i.e., depression and marital problems). Their analyses noted that none of the potential moderator variables, including locus of

control, were significant (Dunn et al., 2001). It can be argued that a reason for this finding may be in the definition, and subsequent measurement, of control beliefs as a moderator. Moderators tend to be variables that change the impact of one variable upon another. Mediators, however, are the mechanism by which one variable affects another. Based upon the FAAR model and the theorized relationship family beliefs have upon capabilities/demands and eventual adaptational outcomes, conceptualizing health locus of control as a mediator could be more appropriate. Therefore, this study posits that health locus of control may also mediate the relationship between demands and family adaptation.

Mastery

In the family systems literature, control and mastery are thought to be equally important in understanding the family's overall definition of a chronic condition and their beliefs regarding their experience with the chronic illness or disability (Rolland, 1994). While on the surface these two concepts may appear very similar, there are differences in the way these concepts can be defined. As noted previously, control involves beliefs regarding the extent to which an individual has personal agency over life events, including a particular disability or illness (Dohrenwend & Dohrenwend, 1981). Mastery, however, involves beliefs regarding the extent to which life events are manageable or comprehensible (Antonovsky, 1987; Antonovsky & Sourani, 1988). Thus, one could believe he/she has mastery over his/her situation without believing in personal control.

There has been a good deal written on the concept of mastery within the literature on individuals with chronic illnesses and disabilities. Within this literature, the concept

of mastery is often defined as sense of coherence (SOC). SOC is a global orientation in which individuals feel confidence that: “1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable; 2) the resources are available to one to meet the demands posed by these stimuli; and 3) these demands are challenges, worthy of investment and engagement.” (Antonovsky, 1987, pp. 19). Combined, the three components of SOC (i.e., comprehensibility, manageability, and meaningfulness) embody mastery-related ways individuals can make meaning of their experiences.

For example, Antonovsky argued that when individuals believe that their environment is comprehensible, or orderable, the nature of stressors and the problems that arise from them are cognitively clearer (Antonovsky, 1987). Likewise, when individuals perceive the demands posed by stressors as manageable, individuals will be more likely to search out appropriate available resources (Antonovsky, 1987). Finally, when individuals perceive their life as meaningful, this perception tends to provide the motivational drive to actively combat stressors (Antonovsky, 1987).

SOC is based on the belief that illness is a normative human experience rather than a pathological one; that is, most individuals and families at some point in their lives must manage health issues. Developed by Antonovsky (1987), SOC adheres to a ‘salutogenesis’ perspective, a perspective in which health and functioning are emphasized rather than the causes of sickness (Antonovsky, 1987). Antonovsky (1987) noted that many factors help families cope with chronic health conditions and it is important to understand how these factors work to reduce the potential negative impact of illness.

The concept of SOC could have a role in how parents understand and manage their experience with a family member's ASD, as well as how these mastery-related beliefs impact the family's overall adaptation. For example, given the relatively uncertain nature of ASDs and variability in the severity of symptomolgy, one could argue that the more chaotic or inexplicable a family perceives their everyday experience to be with their family member's ASD, the harder it is for a family to define and understand their experience and utilize appropriate strategies to address demands that arise. Likewise, the more difficult and unmanageable a family perceives the demands that arise from caring for their family member diagnosed with an ASD, the harder it could be for those families to access and utilize appropriate resources to manage those demands. Finally, if families view their life with their family member diagnosed with an ASD as catastrophic with no redeemable aspects, rather than as challenging but meaningful, families could have more difficulty motivating themselves to actively address demands as they arise. Thus, families with a greater SOC may be more motivated and active in their ASD family member's treatment and obtaining appropriate services, may view their experience as more manageable, and may have greater cognitive clarity regarding the issues that arise due to the demands associated with ASDs.

While theoretically an important construct, SOC has only recently begun to receive greater attention in the literature on families of children diagnosed with developmental disabilities and/or chronic illnesses. In one study, Oelofsen and Richardson (2006) utilized the sense of coherence construct to examine group differences between 59 families of children with a developmental disability and 45 families of

typically developing children in the United Kingdom. This study assumed the importance of SOC on outcomes and focused on describing the differences between the two studied groups. They found that parents of children with a developmental disability consistently reported higher levels of parenting stress and weaker sense of coherence than parents of typically developing children (Oelofsen & Richardson, 2006).

Other studies have gone beyond describing group differences to examine how SOC impacts individual outcomes within specific populations, such as families of children diagnosed with developmental disabilities or chronic illnesses. For example, Margalit and Kleitman (2006), while examining families utilizing a specific early intervention program in Israel, also looked at SOC. Quantitative analysis of responses from 70 mothers of children at risk for developing a developmental disability demonstrated that mothers' level of stress was significantly predicted by their SOC scores. Specifically, the authors noted that the higher the SOC score, the lower level of stress experienced at both the start of the intervention and at its conclusion (Margalit & Kleitman, 2006). This finding, specifically the negative relationship between SOC score and level of individual parental stress, has received some additional support (Margalit, Al-Yagon, & Kleitman, 2006).

One study in the chronic illness and developmental disability literature was found to examine the impact of SOC on family-level outcomes. In this study, the authors examined the impact SOC had on the overall family adaptation of 76 American families and 103 Icelandic families of young children diagnosed with asthma (Svavarsdottir, Rayens, & McCubbin, 2005). Results of this study indicated that, for both mothers and

fathers, family adaptation was directly predicted by SOC. That is, as SOC scores increased, family adaptation did as well (Svavarsdottir, Rayens, & McCubbin, 2005). The authors noted that SOC had an additional indirect impact upon family adaptation. That is, for both mothers and fathers, SOC also moderated the effect of family demands on family adaptation (Svavarsdottir, Rayens, & McCubbin, 2005).

Within the autism-specific literature, three studies were found to have focused specifically on SOC with families of children diagnosed with an ASD. For example, Olsson and Hwang (2002) conducted a quantitative study in Sweden of 216 families of children with autism, intellectual disabilities, or typically developing children. These authors compared SOC levels across these three groups, as well as the impact SOC had on parents' level of depression within each group. Similar to the findings of Oelofsen and Richardson (2006), Olsson and Hwang found that mothers of children with autism had lower SOC levels than mothers of children with an intellectual disability, who in turn had lower SOC levels than mothers of typically developing children (Olsson & Hwang, 2002). In addition, the authors also noted that mothers with low SOC scores also had higher depression scores than mothers with high SOC scores (Olsson & Hwang, 2002). Finally, mothers of children with either an intellectual disability or autism who had low SOC scores scored higher on depression indices than parents of typically developing children who had low SOC scores. Interestingly enough, the authors noted that fathers' SOC scores and depression scores did not significantly differ among the three groups (Olsson & Hwang, 2002).

Sivberg (2002) also examined the relationship between SOC, coping styles, and family strain in parents of children with an ASD. This quantitative study compared 66 parents of children diagnosed with an ASD with 66 parents of typically developing children in Sweden. Results of the study noted a negative relationship between the level of strain on the family and the level of SOC (Sivberg, 2002). That is, the lower the level of SOC, the higher the level of strain (Sivberg, 2002). In addition, the study noted that families of autistic children demonstrated higher levels of strain than families of typically developing children (Sivberg, 2002).

Finally, Mak, Ho, and Law (2007) examined the relationship between SOC, parenting attitudes and stress in families of children diagnosed with an ASD. In their study, the authors surveyed 157 parents of children diagnosed with an ASD in Hong Kong. The study's results indicated that mothers with higher levels of SOC reported less stress than mothers with lower levels of SOC (Mak, Ho, & Law, 2007). The study also indicated that SOC acted as a moderator between autistic symptom severity and parenting stress (Mak, Ho, & Law, 2007).

As this body of literature suggests, SOC is an important construct in promoting positive individual and family outcomes in families managing chronic health conditions. Families with special needs children have consistently demonstrated lower levels of SOC than families of typically developing children. In addition, families of individuals diagnosed with an ASD have also demonstrated lower levels of SOC than other special needs groups, potentially placing them at an increased risk for negative outcomes. Given the influence SOC can have upon intervention effectiveness and family's involvement in

treatment (e.g., Margalit & Kleitman, 2006), understanding the role of SOC in promoting resilience and positive adaptation within families of individuals diagnosed with an ASD is crucial.

All but one of the reviewed studies utilizing the SOC construct focused on the impact SOC has upon individual outcomes such as parental stress or depression. In general, SOC was found to have a significant impact upon these individual outcomes. Less is known, however, about the role SOC plays in family outcomes, such as family adaptation or quality of life. Although one study (i.e., Svavarsdottir, Rayens, & McCubbin, 2005) demonstrated that parental SOC does have an impact upon family-level adaptation, this study examined families of children diagnosed with asthma. Given the theoretical importance of SOC in the family's level of engagement in treatment and management of stress, and the potential between-group differences of families with ASD individuals and families with individuals with other chronic illness or disabilities, it is important to understand the impact parental SOC may have upon family adaptation specifically within families of individuals diagnosed with an ASD. This study posits that, consistent with the Svavarsdottir, Rayens, and McCubbin (2005) finding, parental SOC levels will have a direct influence upon family level outcomes.

Finally, the majority of reviewed studies utilizing the SOC construct have focused on the direct influence SOC has upon outcome measures. Less attention has been given to the indirect role SOC may play in effecting outcomes. What evidence exists (i.e., Mak, Ho, & Law, 2007; Svavarsdottir, Rayens, & McCubbin, 2005) suggests that SOC may play a moderating role in both individual and family outcomes. Given this study's

conceptualization of parental beliefs as the mechanisms through which families' demands and capabilities impact adaptation, this study will examine the extent to which SOC acts as a mediator between family demands and family adaptation.

Family Adaptation

Families of individuals diagnosed with an ASD play an important role in the treatment of ASDs. Current best practice paradigms of working with individuals diagnosed with an ASD note that families are essential elements of optimal interventions with children diagnosed with an ASD and children with other disabilities (e.g., Marcus, Kunce, & Schopler, 2005; National Research Council, 2001; Parish et al., 2001). Congruent with developmental systems views of optimal development (e.g., Bronfenbrenner, 1986; Ford & Lerner, 1992; Lerner, 1991; Lerner, Walsh, & Howard, 1998), favorable treatment outcomes of a special needs child are not only dependent upon features related to the particular illness/disability or characteristics of that individual child, but also features of the family system (e.g., Patterson, 2005; Rolland, 1994).

Chronic illness and/or disability impacts both the individual and the whole family system (Patterson, 2005; Summers et al., 2005; Turnbull, Turnbull, Erwin, & Soodak, 2006). This is true as well for families of individuals diagnosed with an ASD. Many aspects of the family's experience, such as family relationships, relationships with non-family members, parenting practices, financial resources, and emotional resources can be influenced by a family member's ASD (e.g., DeMyer & Goldberg, 1983). Additionally, family members in families of individuals diagnosed with an ASD may necessarily hold

additional roles beyond those found in 'typical' families, including life-long direct caregiver, advocate, co-therapist, and educator. These roles necessitate skill sets that may be different from, or in addition to, those often associated with families of typically developing children. Thus, 'normal' parenting alone may not sufficiently address the domain deficits found in ASDs (Bristol & Schopler, 1984). The demands placed upon the families of ASD individuals may necessitate adaptation in the roles and relationships that family members assume (e.g., more traditional parenting roles, different sibling relationships, etc.) or limit family members in some manner (e.g., work status, recreational activities and time, social connections, etc.) (Bristol, 1984, 1985, 1987a, 1987b; Bristol & Schopler, 1984; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Gray, 2002).

Accordingly, it becomes imperative to understand not only the impact a child's ASD has upon the family system, but also how best to support the family's adaptation to their family member's condition. To this end, the construct of family quality of life may be a useful indicator of family adaptation. The following section will first define family adaptation and family quality of life, and then examine the current literature on family quality of life within the ASD and chronic illness and disabilities literature.

Family Quality of Life

In utilizing the definition of family adaptation presented within the FAAR model (Patterson, 1988, 2002), one must look beyond individual mental health outcomes as measures of adaptation and include family outcomes. Traditionally, research examining the impact of children with disabilities on their families focused on the psychosocial

functioning of family members or specific family relationships (e.g., marital satisfaction). The FAAR model suggests, however, that measures of family adaptation must go beyond unidimensional and individual-focused outcomes to reflect both positive individual growth and relationships between family members (i.e., within-family) as well as the family's ability to successful meet its vulnerable family members' needs within the community (i.e., family-community) (Patterson, 1988, 2002). In doing so, adaptation becomes strength-focused, facilitative rather than pathological, and context sensitive.

Consistent with this definition of family adaptation is the concept of family quality of life. Optimal family quality of life (FQOL) is defined as conditions in which the family's needs are met, family members are able to do things that are important to them, and family members enjoy their life together as a family (Park et al., 2003; Turnbull, Turbiville, & Turnbull, 2000). In this context, the term 'family' is used to represent individuals who define themselves as part of a family, whether they are actually related or not, and who care for or support each other (Park et al., 2003; Turnbull et al., 2000).

Family quality of life is thought to encompass four main principles: 1) family members influence each other; 2) domains of FQOL interact and impact each other; 3) FQOL can change over time; and 4) the definition of FQOL is dependent upon what a family defines as "quality" (Park, Turnbull, & Turnbull, 2002). While the constructive meaning of FQOL may change from family to family, consistent basic aspects of quality of life are thought to exist across families. Some authors have proposed that these basic aspects can be categorized into five general domains for families managing chronic

illnesses and disabilities. These general domains include: 1) family interactions, 2) parenting, 3) emotional well-being, 4) physical and financial well-being, and 5) disability related support (Park et al., 2003; Turnbull et al., 2004; Wang et al., 2004). These five domains are consistent with the within-family (e.g., family interactions, parenting, emotional well-being, and physical and financial well-being) and family-community (e.g., disability related support) factors promoted by the FAAR model.

While the literature on family quality of life is in its infancy, some studies within the chronic illness and disability literature have examined this topic. Several of these studies support the notion that having a family member with a chronic illness or disability has the potential to negatively impact the family's quality of life in comparison to families of typically developing children. For example, Browne and Bramston (1996) conducted a study that compared 44 parents of intellectually disabled (ID) children with 58 parents of typically developing children. The study found that, while there was no difference between these two groups on how each group rated the importance of quality of life (QOL) domains, families of children with an ID had lower overall QOL scores than families of typically developing children. Families of children diagnosed with an ID also had significantly lower scores than families of typically developing children on specific QOL domains, including material well-being, health, intimacy and community involvement (Browne & Bramston, 1996). Other studies have noted similar findings. That is, families of children with a disability report lower scores on family quality of life measures as compared with families of typically developing children (Brown et al., 2006; Ones et al., 2005).

Other studies within the chronic illness or disability literature have examined the relationship between disability-specific factors and family quality of life. For example, Williams and colleagues (2003) conducted a study with 200 parents of children diagnosed with epilepsy. This study examined the relationship between several disability-specific factors and the relationship these factors had with overall family quality of life. Results indicated that the family's quality of life was negatively impacted by the uncertainty of epileptic episodes (i.e., poorly controlled epilepsy) and the presence of comorbid conditions (Williams et al., 2003). Additionally, in a study of 130 fathers and 234 mothers of children with a variety of disabilities, Wang and colleagues (2004) found that severity of the disability was a significant predictor of both mothers' and fathers' reports of satisfaction with family quality of life (Wang et al., 2004).

A few studies have also examined the relationship between parental factors and family quality of life within families of individuals with chronic illnesses or disabilities. For example, Williams and colleagues (2003) noted that a family's quality of life was negatively influenced by heightened parental anxiety (Williams et al., 2003). Likewise, in a study of 46 mothers of children diagnosed with cerebral palsy and 46 mothers of typically developing children, Ones and colleagues noted a relationship between quality of life and parental depression (Ones et al., 2005). Specifically, for mothers of children with cerebral palsy, the more depressed a mother was, the lower her ratings of quality of life (Ones et al., 2005).

Only two studies were found that specifically examined the family's quality of life in families of individuals diagnosed with an ASD. The first examined family quality

of life across families of typically and atypically developing children. Specifically, Brown and colleagues (Brown et al., 2006) examined group differences in family quality of life between families of children with Down Syndrome, children diagnosed with an ASD, and typically developing children. This study found that families with typically developing children demonstrated significantly higher levels of quality of life than the other groups (Brown et al., 2006). The authors further noted that, in all but one domain of family quality of life, families of children diagnosed with an ASD had the lowest satisfaction with family quality of life domains (Brown et al., 2006). These domains included career, leisure, community/civic involvement, financial well-being, health, family relations, support from other people, support from disability-related services (Brown et al., 2006).

A second study also examined factors that impact mother's quality of life within families of children diagnosed with an ASD. Specifically, Shu and Lung (2005) conducted a study examining the effects of a support group intervention for mothers of children diagnosed with an ASD in China. In general, they noted that subjective well-being and employment status had a significant impact on mother's quality of life. That is, mothers with higher levels of well-being and who were employed reported greater satisfaction with their quality of life (Shu & Lung, 2005).

As a whole, this body of literature suggests that family quality of life is impacted by a child's disability. In addition, several factors, including the uncertainty of a health condition, severity or 'pile-up' of symptoms related to a condition, and parental well-being can influence the extent to which quality of life is impacted. As noted, this

literature is in its infancy and very few studies were found that examined family quality of life in families of individuals diagnosed with an ASD. Therefore, this study will add to this current literature by specifically examining family quality of life within families of individuals diagnosed with an ASD.

As these studies have suggested, factors such as severity of a disability and the level of uncertainty regarding a disability's symptom expression can directly impact family quality of life. These studies, however, have not looked at the impact these specific family demands have upon the quality of life of families of individuals diagnosed with an ASD. Therefore, this study will also examine whether or not the relationships that were reported on in the broader chronic illness and disability literature also apply to families of individuals diagnosed with an ASD.

Finally, as proposed by the FAAR model, family beliefs are thought to mediate the relationship between demands, such as uncertainty and disability severity, and family adaptation. A review of the literature found no studies that have previously examined this hypothesis utilizing family quality of life as a measure of family adaptation. Therefore, this study will also examine the extent to which family beliefs, particularly those of parents, such as level of optimism, views of control and beliefs regarding mastery, mediate the relative impact uncertainty and perceived ASD severity have on families of individuals' diagnosed with an ASD's quality of life.

Conclusion: The Current Study

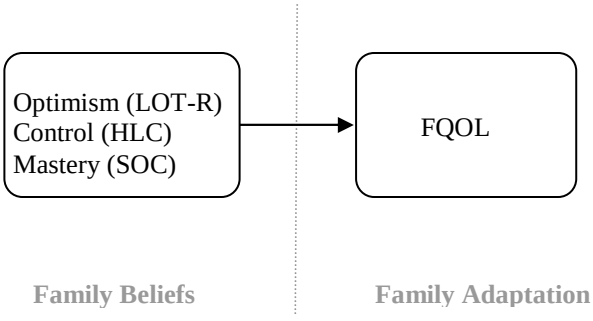
This chapter has reviewed the theoretical and empirical literature on the experiences of families with children diagnosed with an ASD. These experiences are both similar to, and different from, experiences of families of children with other disabilities or chronic health conditions (Bristol & Schopler, 1984). Given the historical view of the family of individuals diagnosed with an ASD, past research and interventions with this population have either pathologized the family and their experiences or neglected their potential role in influencing long-lasting positive change in the individual diagnosed with an ASD's treatment. This study suggests that, by utilizing strength-based and systems-focused theories such as the FAAR model (e.g., Patterson, 1998, 2005) and the Family Systems-Illness Model (e.g., Rolland, 1994, 2003) to guide research design and inform study findings, practitioners working with families of individuals diagnosed with an ASD may gain valuable information regarding potential intervention areas that promote positive functioning in both the individual diagnosed with an ASD and his/her family.

Therefore, this study used the FAAR model and Family Systems-Illness Model to identify specific factors for inquiry, as well as the hypothesized relationships between the identified factors. Specifically, this study examined the relationship between identified demands, family beliefs, and family adaptation in families of individuals diagnosed with an ASD. The variable family quality of life (FQOL) was selected to represent family adaptation, the outcome variable. FQOL was deemed a good fit for the definition of family adaptation used in this study given the dynamic relationship individuals diagnosed

with ASD have with their families (e.g., Bristol, 1984, 1985, 1987b; Bristol & Schopler, 1984; Brown et al., 2006; DeMyer & Goldberg, 1983; Gray, 2002), as well as the current recommendation for family-centered practice in individuals diagnosed with an ASD's treatment (e.g., Marcus, Kunce, & Schopler, 2005; National Research Council, 2001).

Next, this study proposes that beliefs held by family members, particularly parents or other primary caregivers, significantly predict family adaptation. As the above literature review suggests, beliefs such as optimism, control (as measured by health locus of control), and mastery (as measured by sense of coherence) play important roles in influencing positive individual and family outcomes in families faced with a variety of chronic health conditions, including ASDs. Thus this study suggests that when family members have more optimistic views, a greater sense of internal health locus of control (HLCInt) or balanced internal and external health locus of control (HLCInt and HLCExt, HLCP, or HLCO), and a greater sense of coherence (SOC), they will also report greater family quality of life (FQOL). Figure 1 provides a visual representation of the proposed relationship between these variables.

Figure 1. Family beliefs as predictors of family quality of life



Finally, beliefs held by family members are thought to play a vital role in mediating or moderating the relative impact demands have on overall family adaptation (Patterson, 2005). Since this study suggests that optimism, health locus of control, and sense of coherence are the mechanisms through which demands influence family adaptation, this study focused on the extent to which these factors mediate the relationship between demands upon the family and family adaptation. To test this mediational relationship, this study first examined the impact that two specific demands, the uncertainty related to a family member's ASD and the level of perceived severity of the ASD, have upon family quality of life (FQOL), and then examined the extent to which optimism, health locus of control (HLC), and sense of coherence (SOC) mediate this relationship. Figures 2 and 3 provide a visual representation of the mediational relationship proposed in this study.

Figure 2. Family beliefs mediating the relationship between uncertainty and family quality of life

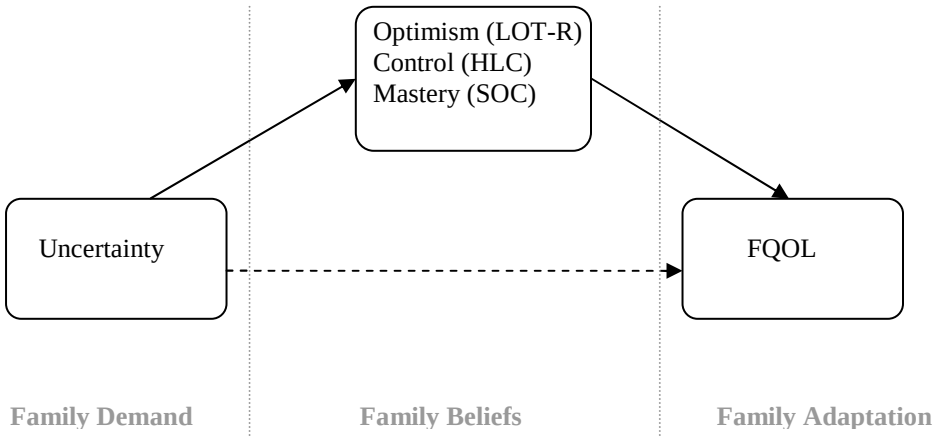
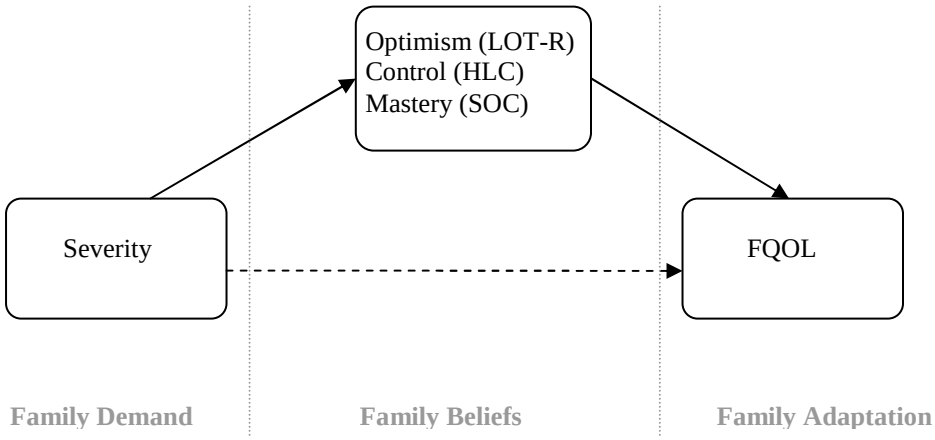


Figure 3. Family beliefs mediating the relationship between perceived severity and family quality of life



Hypotheses

This study utilized the following hypotheses to test the relationship between demands (i.e., uncertainty and perceived severity), family members' beliefs (i.e., optimism, health locus of control, and sense of coherence) and overall family adaptation (i.e., family quality of life).

General Hypothesis 1:

Family members' beliefs significantly relate to family adaptation.

Specific Hypotheses 1:

1.a. Level of optimism, as measured by dispositional optimism (LOT-R), significantly predicts family adaptation, as measured by family quality of life (FQOL). That is, greater level of optimism predicts greater FQOL.

1.b. Control beliefs, as measured by health locus of control (HLC), significantly predict family adaptation, as measured by family quality of life (FQOL).

1.b.i. Higher reported internal HLC (i.e., HLCInt) predicts greater FQOL.

1.b.ii. The combination of high internal and external HLOC (i.e., HLCInt and HLCExt, HLCP, or HLCO) predicts greater FQOL than the combination of low internal and external HLC.

1.c. Mastery beliefs, as measured by sense of coherence (SOC), significantly predict family adaptation, as measured by family quality of life (FQOL). That is, greater levels of SOC predict greater FQOL.

General Hypothesis 2:

Family members' beliefs act as mediators between the perceived severity of a family member's ASD and family adaptation.

Specific Hypotheses 2:

2.a Perceived severity (PCQ) significantly predicts family adaptation, as measured by family quality of life (FQOL). That is, the greater the perceived level of severity (PCQ), the lower the FQOL.

2.b Optimism, as measured by dispositional optimism (LOT-R), mediates the relationship between perceived severity (PCQ) and FQOL.

2.c Control beliefs, as measured by health locus of control (HLC), mediate the relationship between perceived severity (PCQ) and FQOL.

2.d Mastery beliefs, as measured by sense of coherence (SOC), mediate the relationship between perceived severity (PCQ) and FQOL.

General Hypothesis 3:

Family members' beliefs act as mediators between uncertainty and family adaptation.

Specific Hypotheses 3:

3.a Uncertainty (PPUS) significantly predicts family adaptation, as measured by family quality of life (FQOL). That is, the greater the reported uncertainty (PPUS), the lower the FQOL.

3.b Optimism, as measured by dispositional optimism (LOT-R), mediates the relationship between uncertainty (PPUS) and FQOL.

3.c Control beliefs, as measured by health locus of control (HLC), mediate the relationship between uncertainty (PPUS) and FQOL.

3.d Mastery beliefs, as measured by sense of coherence (SOC), mediate the relationship between uncertainty (PPUS) and FQOL.

The next chapter will describe this study's research design, participants, specific measures, procedure, and analyses.

CHAPTER 3

Method

Research Design

This study uses a survey, cross-sectional design that utilizes quantitative methods for data collection. Three open-ended questions are also included. Two questions ask about complementary or alternative treatments that the individual diagnosed with an ASD previously used or currently uses. One open-ended question asks participants to identify one domain (e.g., lack of communication; self injurious behaviors; sleep disturbance, etc.) related to their child's ASD that has had the most severe impact upon the family.

A power analysis for multiple regression was conducted prior to the start of this study. Cohen (1992) suggests that for a study utilizing 5 predictor variables and an alpha set at .05, a sample size of approximately 91 participants would be required to detect a medium effect size.

Participants

The study utilized data collected from 207 biological parents or other primary caretakers (e.g., step-parents, foster parents, etc.) of individuals who have been diagnosed with an ASD. For the purpose of this study, parent or primary caretaker is defined as the adult(s) who assumes the role of responsibility in caring for, and making treatment decisions for, the individual diagnosed with an ASD. Both male and female parents or primary caretakers were encouraged to participate. Marriage status or family composition was assessed, but was not used to prohibit individuals from participating.

Participants were limited to parents or caretakers of individuals who had received a formal diagnosis consistent with either Autism, PDD-NOS, or Asperger's Disorder, as outlined in the DSM-IV-TR (APA, 2000). The specific diagnosis was ascertained by a question on the demographic information section. While participation was limited to parents or caretakers whose children are at least 2 years old, no other age limitation was set for the individual diagnosed with an ASD, thus allowing for the inclusion of parents or caretakers of adult children diagnosed with an ASD.

Using convenience sampling, the participants were recruited from a variety of organizations within Pennsylvania, including ten autism support organizations, four private specialized schools, and one service provider organization. This study used two recruitment approaches. The first involved recruiting participants from ten Pennsylvania-specific autism support organizations via the internet (i.e., member listserv). The second recruitment approach involved having four private specialized schools and one service provider organization assist in accessing potential participants via mail. Recruitment of participants was dependent upon the approval of the moderators of the identified listservs and support groups and the administrators of the identified provider organizations and private specialized schools. Recruitment procedures are further described in the procedure section.

Measures

The measures utilized in this study assess three constructs: 1) family adaptation; 2) family beliefs; and 3) demand factors (please see Table 1). This study also collected

demographic information. The self-report measures are described below. The measures were presented to participants in this order to reduce potential participant bias. Specifically, the questionnaires were presented to participants in the following order so as to keep participants blind to the hypotheses of this study as well as to ensure that questionnaires assessing demand factors do not unduly influence how participants answer the family adaptation and family belief questionnaires.

Table 1.
Study Constructs, Variables, & Measurements

Construct	**Variables**	**Instrument**	**Number of Items**
Family Adaptation			
	Family Quality of Life	Family Quality of Life Survey (FQOL)	25
Family Beliefs			
	Optimism (Global)	Life Orientation Test – Revised (LOT-R)	10
	Control (ASD-specific)	Multidimensional Health Locus of Control – Form C (MHLC-C)	18
	Mastery (Global)	Orientation to Life Questionnaire, short form (SOC-13)	13
Demand Factors			
	Uncertainty related to individual's ASD	Parent Perception of Uncertainty Scale (PPUS)	31
	Perceived severity of individual's ASD	Parental Concerns Questionnaire (PCQ)	13

Family Adaptation

As noted in Chapter 2, the family's adaptation to a family member's ASD is the outcome of focus in this study. Family adaptation has been defined as encompassing individual growth, family member relationships with each other (i.e., within-family), and

the family's relationships with its community (Patterson, 2002). For this study, the concept of family quality of life was selected to represent family adaptation. Family quality of life has been defined as the extent to which the family's needs are met, family members are able to do things that are important to them, and family members enjoy their life together as a family (Park et al., 2003; Turnbull, Turbiville, & Turnbull, 2000). Thus, family quality of life provides a good fit to the definition of family adaptation used in this study.

Family Quality of Life. This study selected the Family Quality of Life Survey (FQOL; Beach Center on Disability, 2003, 2005; please see Appendix A) to operationalize the concept of family adaptation. The FQOL is a 25-item measure that assesses the quality of life of families of individuals with disabilities. The survey consists of five subscales: 1) family interaction, 2) parenting, 3) emotional well-being, 4) physical/material well-being, and 5) disability-related support. While scores can be reported as either an aggregate or by each subscale, this current study utilized the total FQOL score. Although the FQOL asks participants to rate both the importance of, and satisfaction with, a particular item, satisfaction is the primary response format and can be used alone (Wang et al., 2004). For this study, only the satisfaction ratings were used to generate a total FQOL satisfaction score, with higher scores reflecting greater satisfaction with family quality of life. Items are rated according to a five-point Likert scale where satisfaction is rated from "very dissatisfied" to "very satisfied." An example of an item is "My family enjoys spending time together."

Overall, the FQOL has demonstrated good psychometric properties. Cronbach's alphas for the FQOL were reported to be 0.94 for the Importance ratings and 0.88 for the Satisfaction ratings (Hoffman et al., 2006). Support for the convergent validity of both the overall FQOL and subscale-level FQOL has been reported; specifically, the FQOL was found to correlate with relevant existing measures, including the Family APGAR and the Family Resource Scale (Hoffman et al., 2006). Additionally, Wang and colleagues (Wang et al., 2006) tested the stability of this measure across mothers and fathers and found that both mothers and fathers had statistically identical ratings of both importance and satisfaction, and thus concluded that a single parent's scores may be used as representative of family scores in situations where scores of other family members would be difficult to collect (Wang et al., 2006).

Family Beliefs

As noted in Chapter 2, family beliefs are beliefs that family members hold about a family member's health condition. These beliefs are thought to directly and indirectly impact the adaptation, coping, and resilience of families (e.g., Lazarus & Folkman, 1984; McCubbin & McCubbin, 1993; Roland, 1994). Three family beliefs were selected for this current study: optimism, control, and mastery. Optimism encompasses the extent to which an individual has global expectations of good outcomes. Control beliefs are defined as the beliefs individuals hold regarding their personal influence over the course or outcome of their family member's ASD. Finally, mastery beliefs encompass the extent to which individuals feel their lives are comprehensible, manageable, and meaningful. Measures operationalizing these concepts are described as follows.

Optimism. This study used the Life Orientation Test - Revised (LOT-R; Carver & Scheier, 2003; Scheier, Carver, & Bridges, 1994; please see Appendix B) to operationalize the concept of optimism. The LOT-R is a measure of dispositional optimism, or the extent to which individuals view life optimistically. As such, the LOT-R is congruent with the definition of optimism utilized in this study. The six item (plus four 'filler' items that are not utilized in scoring) scale uses a 5-point response category (1 – 'strongly disagree' to 5 – 'strongly agree'), with a total score ranging from 5 to 30. Higher scores reflect a more optimistic view. A sample item includes "In uncertain times, I usually expect the best."

The LOT-R has been widely used within the social sciences and demonstrates good psychometric properties. Overall internal consistency for the LOT-R is reported to be good, with Cronbach's alpha ranges from high .70s to low .80s (Carver & Scheier, 2003). With respect to special needs populations, Cronbach's alpha have been reported to be .75, .81, and .87, respectively, for mothers of adults with Down Syndrome, schizophrenia, and autism (Greenberg et al., 2004). The LOT-R has demonstrated significant correlations in the expected directions with other constructs, including depression, hopelessness, self-esteem, and perceived stress (Scheier, Carver, & Bridges, 1994). Further evidence of validity includes scores of the LOT-R being strongly correlated with physical and psychological well-being and relatively unrelated to measures of social desirability (Scheier and Carver, 1992).

Control. This study used the Multidimensional Health Locus of Control scale – Form C (MHLC-C; Wallston, Wallston, & DeVellis, 1978; Wallston, Stein, & Smith,

1994; please see Appendix C) to operationalize the concept of control beliefs. The MHLC-C is one of a series of scales that assess individual's health related control beliefs. The MHLC-C is designed to flexibly assess an individual's locus of control beliefs regarding an existing illness or disease, rather than general health beliefs (Wallston, 2005). The MHLC-C is comprised of 18 items that reflect four dimensions or subscales: 1) Internal health locus of control (i.e., HLCInt); 2) Chance health locus of control (i.e., HLCExt); 3) Doctors/Professionals (i.e., HLCP); and 4) Other People (i.e., HLCO). Chance, Doctors/Professionals, and Other People reflect subtypes of external health locus of control. Total scores are calculated for each subscale, with higher scores indicating greater attribution of control to that particular source. While often the scores of the four dimensions have been used separately (e.g., internal v. chance), others have begun to include interactions between dimensions (e.g., high internal & high powerful others) (Green, 2004).

The MHLC-C was selected for this study specifically because it is a generic, easily modifiable scale created specifically to assess a variety of illnesses or disabilities (Wallston, 2005). Accepted language substitutions include exchanging the word "condition" with the specific illness or disability, and exchanging "powerful others" for either "doctors" or "professionals" depending upon the condition (Wallston, Stein, & Smith, 1994). For this study, the MHLC-C was adapted to better reflect the experience of families of individuals diagnosed with an ASD. Using the recommendations of Wallston and colleagues (Wallston, Stein, & Smith, 1994), the word 'condition' was replaced with 'autism spectrum disorder' and 'powerful others' was replaced by 'professionals.'

Sample items include “Other people play a big role in whether my child’s autism spectrum disorder improves, stays the same, or gets worse” and “Following professionals’ advice to the letter is the best way to keep my child’s autism spectrum disorder from getting worse.”

The MHLC-C is considered to be reliable, with Cronbach alphas for the subscales ranging between 0.70 – 0.87 (Wallston, Stein, & Smith, 1994). Strong evidence for convergent, construct, and criterion-related validity has been reported (Wallston, 2005). Specifically, Wallston and colleagues note that concurrent validity was established with the original MHLC-B since the MHLC-C subscales correlated with their respective subscale counterparts in the MHLC-B (Wallston, Stein, & Smith, 1994). Wallston and colleagues (Wallston, Stein, & Smith, 1994) also reported that significant relationships exist between the subscales of the MHLC-C and corresponding subscales on the Levenson locus of control scale (Levenson, 1973). Wallston and colleagues further report that predicted correlations exist between the MHLC-C and the distinct, but related constructs of helplessness and depression (Wallston, Stein, & Smith, 1994).

Mastery. This study used the short version of the Orientation to Life Questionnaire, also known as the Sense of Coherence Scale (SOC-13; Antonovsky, 1987; Antonovsky & Sourani, 1988), to operationalize the concept of mastery beliefs. The SOC-13 is a 13 item scale that rates individuals’ sense of the comprehensibility, manageability and meaningfulness of that person’s life events and is thus congruent with the definition of mastery utilized in this study. Respondents are asked to rate the extent to which they endorse the 13 statements on a seven-point Likert scale, from (1) ‘very

often' to (7) 'very seldom' or 'never.' Unlike the full version SOC (SOC-29), the short version is only used to gain a total score and should not be used for subscale scores. Since this study plans to only utilize the total SOC score, using the SOC-13 over the SOC-29 is warranted. Higher total scores reflect greater sense of coherence. Sample items of the scale include, 'How often do you have feelings that you're not sure you can keep under control?' and 'How often do you have the feeling that there's little meaning in the things you do in your daily life?'

The SOC-13 has shown good psychometric properties in previous studies. In a systematic review of the reliability of the SOC-13, Eriksson and Lindstrom found that, across 127 studies, Chronbach's alphas ranged from 0.70 - 0.92 and test-retest correlations ranged from 0.69 – 0.78 (Eriksson & Lindstrom, 2005). Evidence of the validity of the full SOC-29 and the short form SOC-13 includes moderate to good correlations with scores on related constructs, including measures of health and well-being (e.g., General Health Questionnaire, Health Index, Hopkin's Symptom Checklist, Mental Health Inventory), depression, anxiety, and self-esteem (Eriksson & Lindstrom, 2005).

Demand Factors

As noted in Chapter 2, demand factors are factors that place stress or strain upon the family and challenge the family's overall functioning. Two demand factors were selected for this current study: uncertainty and perceived severity of an individual's ASD. Uncertainty encompasses the extent to which the participant is able to predict what will happen to their child, what consequences are associated with a diagnosis of ASD, and

what the diagnosis of ASD means. Perceived severity encompasses the extent to which the participant views the functional or behavioral symptoms of their child's ASD as problems. Measures operationalizing these concepts are described as follows.

Uncertainty. This study used the Parent Perception of Uncertainty Scale (PPUS; Mishel, 1983), also known as the Mishel Uncertainty in Illness Scale – Parent/Child Form, to operationalize the concept of uncertainty. The PPUS is a 31 item scale that is designed to measure the amount of uncertainty a parent has about their child's illness or other health related condition. Uncertainty encompasses four factors: ambiguity, lack of clarity, lack of information, and unpredictability. Ambiguity refers to the absence or vagueness of information regarding the planning and carrying out of care for the child (Mishel, 1997). Lack of clarity refers to the extent to which information about the child's treatment and the system of care is perceived as intricate and ill-defined (Mishel, 1997). Lack of information refers to the absence of information concerning the diagnosis and seriousness of the illness or condition (Mishel, 1997). Unpredictability refers to the inability to make daily or future predictions concerning the condition's symptomatology and outcome (Mishel, 1997). Thus, the definition of uncertainty utilized by the PPUS is consistent with that adopted by this current study.

The PPUS asks respondents to rate items on a 5-point scale ranging from (1) strongly disagree to (5) strongly agree. Scores from the four factors of the PPUS (i.e., ambiguity, lack of clarity, lack of information, and unpredictability) can be reported separately from each other. The PPUS also yields a total uncertainty score that is the sum

of all dimensions, with higher scores indicating greater uncertainty. For this study, the total uncertainty score was utilized.

The PPUS has been used to assess parental uncertainty within populations faced with a variety of health-related conditions, including Spina Bifida, cystic fibrosis, cancer, multiple sclerosis, irritable bowel syndrome, and various mental health issues (Mishel, 1997). Mishel provides guidelines for limited language substitution so as to better reflect a specific condition. For example, Mishel notes that items referring to 'pain' can be changed to 'symptoms' or the specific symptom most prevalent in the condition being addressed (Mishel, 1997). For this study, these guidelines were used to adapt the PPUS to better reflect ASDs. Specifically, the word 'illness' was changed to 'autism spectrum disorder,' the word 'pain' was changed to 'symptom,' and 'doctor' to 'professional.' Sample items include "The purpose of each treatment is clear to me" and "I can depend on the professionals working with my child to be there when I need them."

Psychometric data for the PPUS note coefficient alphas for specific factors to be in the moderate to high range (coefficient alpha = .67 - .89) (Mishel, 1997). In addition, the PPUS total scale is reported to have high internal consistency ($\alpha = .91$) and strong reliability ($r = .86$ to $.93$) (Carpentier, Mullins, Chaney, & Wagner, 2006; Mishel, 1983). Face validity of Mishel's uncertainty scales was established by a group of doctors, nurses, and medical and surgical patients who checked the wording of the questions (Mishel, 1997). Factor analysis of the PPUS also supports its construct validity (Mishel, 1983, 1997). In addition, a significant positive relationship between uncertainty and a parent's judgment of the seriousness of their child's illness ($r = .16$, $p<.004$) supports the

predicted relationship between these variables and further supports the construct validity of the PPUS (Mishel, 1983).

Studies of related Mishel uncertainty scales (i.e., MUIS, MUIS-C) also provide support for the validity of this group of scales. For example, the Mishel Uncertainty in Illness Scale (MUIS), a similar scale that measures the individual's own level of uncertainty regarding their health condition, distinguishes between groups of individuals in the diagnostic phase of an illness, a time when uncertainty is expected to be heightened, and groups with an established diagnosis, a time when uncertainty is expected to exist at a lesser level ($F(2,250)=23.97$, $p=<.001$) (Mishel, 1981). Uncertainty has been shown to significantly correlate with ratings of stress in hospitalized medical patients ($r = .35$, $p<.001$) and with lack of comprehension in cancer patients on their first day of treatment ($r = -.56$, $p<.002$), confirming predictions about uncertainty and these theoretically-related constructs (Mishel, 1981).

Severity. This study used the Parental Concerns Questionnaire (PCQ; McGrew et al., 2007; please see Appendix D) to operationalize the concept of perceived severity of an individual's ASD. The PCQ is a 13 item questionnaire that assesses the perceived severity of core diagnostic and associated psychiatric symptomatology of ASDs, including language use, sleep disturbance, aggression, and self-injurious behavior. This questionnaire was developed based on problems reported in the ASD literature, as well as on the types of problems commonly reported by families in clinical referrals. Thus, this questionnaire is not a diagnostic tool, but rather reflects issues families commonly face and define as problems. Since the literature notes a range of behavioral symptoms

impacting the families of ASD individuals, including communication deficits, aggressive behaviors, self-injurious behaviors, etc., which go beyond the diagnostic criteria for specific ASD classifications, the PCQ provides a brief way in which to ascertain the parents' definition of ASD severity in terms of both diagnostic-specific deficits as well as related behavioral symptoms.

The Parental Concerns Questionnaire (PCQ) asks parents to describe the extent to which they consider a symptom to have been a problem within the previous month by rating the problem's severity on a scale of 1-4, with (1) representing no problems, (2) representing mild problems, (3) representing moderate problems, and (4) representing severe problems. Each symptom is identified and a descriptor of that symptom is provided. For example, for the symptom of "anxiety," a sample descriptor is "shows distress from new situations or crowds." Higher scores reflect greater perceived severity of presenting problems. Item by item analysis can be utilized, as well as a total PCQ score reflecting perceived severity of overall ASD symptoms. For this study, the overall score was utilized as a measure of overall perceived severity of the individual's ASD.

The PCQ is reported to have good psychometric properties. Internal consistency, using Chronbach's alpha, is reported to range between 0.78 - 0.93 (McGrew et al., 2007). The validity of most of the PCQ items was established by demonstrating concordance between PCQ items and standardized assessment tools measuring the same domains, including the Child Behavior Checklist, the Child Sleep Habits Questionnaire, the Repetitive Behavior Scales – Revised, and the Autism Diagnostic Observation Schedule (McGrew et al., 2007). Of the items that did not demonstrate significant correlation with

the comparative assessment tools (i.e., social interactions, aggression, mood swing), McGrew and colleagues suggest that this may be the result of sample size effect and restricted range of the ASD group (i.e., all relatively high functioning receiving no medications) (McGrew et al., 2007).

Demographic Information

Demographic Survey. This survey was designed by the investigator to collect general information regarding the participant and the family member diagnosed with an ASD (please see Appendix E). Participants were asked to provide the following demographic information: gender and age of participant, race of participant, relationship of participant to ASD family member, participant's level of education, marital status and work status of participant, family level of income, number of children diagnosed with an ASD in household, current age of child diagnosed with an ASD, gender and race of the child diagnosed with an ASD, the specific diagnosis of the child, age of child at diagnosis, and living situation of child. In addition, basic information regarding services were obtained, including the number of hours of behavioral services and/or therapies (i.e., "wrap around"), educational services and/or therapies (i.e., "school-based" as designated by IFSP or IEP), private services and/or therapies (i.e., state paid or out of pocket), and adult-focused services, therapies or activities, with corresponding satisfaction ratings for each group. Two qualitative questions invited participants to identify past and current complementary or alternative treatments used with the individual diagnosed with an ASD. Finally, an additional qualitative question invited participants to identify the one developmental or behavioral area that has had the most significant impact on the family.

Procedure

Email requests were sent to the moderators of identified Pennsylvania online autism support organizations asking permission to distribute a description of this study (Appendix F). Additionally, administrators of identified Pennsylvania service provider organizations and private specialized schools were contacted via phone or email and asked for permission to distribute a description of this study to the families who utilize their services (Appendix G). These organizations were encouraged to ask questions regarding this study and were provided with a copy of the materials potential participants would receive (i.e., request for participation letter, informed consent, and paper survey materials). Written permission was obtained from all participating sites and organizations prior to obtaining consent from the institutional review board at Boston College. Once consent from Boston College's institutional review board was obtained, potential participants were recruited from participating support organizations, provider organizations, or schools.

Given the desire to access as many potential participants as possible, as well as to ensure a diverse sample, this study utilized two simultaneous data collection procedures. One data collection procedure was through a web-based survey hosted at Psychdata.com. Psychdata.com is a secure online survey service that specializes in social science data collection and management. For participating online autism listservs and support groups, the request for participants consisted of a description of the study that included the purpose of the study and the URL address (Appendix H). At this URL address, participants were asked to indicate if they were a new or returning participant (Appendix

I). If they were a new participant, they were asked to read and give their informed consent to participate (Appendix I) and then complete the study's measures and demographic information survey. If they were a returning participant (i.e., saved and exited the survey prior to completion), they were directed to the page of the survey at which they left off and asked to proceed. This study chose to utilize a "save and return" policy (i.e., ability to log out and return to the study) given the length of the survey and the desire to respect participants' time. While the "save and return" function of this web-based survey did use email addresses as a way for participants to log into the survey, this information was kept completely separate from the survey data itself and could not be linked to the answers participants provided. The "save and return" option allowed participants to only continue forward from the point they left off and did not allow them to make changes on questions already completed. Answers to survey questions were not mandated so as to allow participants the option to answer only questions with which they were comfortable.

At the completion of the web-based survey, participants were directed to an additional debriefing page that included the primary investigator's contact information, for any additional questions they had, as well as an area to indicate whether or not they wanted to be entered into a drawing. To participate in the drawing, participants were asked to provide their name and email address by which they would like to be contacted if they should win. Participants were reminded that their identifying information would be kept separate from the survey information. The web-based survey was designed accordingly. The drawing was for one of ten $50 gift certificates to their choice of the

following retailers: Amazon.com (an internet-based retailer), Target, Wal-Mart, or WaWa (a prominent Pennsylvania gas and convenience company). Information regarding the drawing was provided to participants in the initial description of the study and in the informed consent.

The second data collection procedure utilized a traditional paper-based approach. Specifically, for participating provider organizations and private specialized schools, a print form of this survey, request for participation (Appendix J), and the informed consent letter (Appendix K), was sent home directly from these schools or programs to families utilizing their services. This alternative print method of collecting data was an attempt to provide those families with limited or no access to computers or the internet, and those families not a part of a support group or listserv, an alternate way to participate in this study. Each participant accessed in this manner was provided a packet containing a print copy of a request for participation cover letter, two consent forms, a copy of the survey, and a postage-paid envelope in which to return the completed packet. In the request for participation letter, participants were also provided the option of completing this survey online. Each participant utilizing the paper survey format was asked to return a completed survey and one completed consent form (the other was for his/her records) in the provided postage-paid envelope. Participants were also given the choice to remain anonymous or provide their name, email address (if applicable), and mailing address on the consent form so that they could also be entered into the drawing.

Ensuring anonymity was of utmost importance in this study. To ensure anonymity, the following procedures were utilized. For the web-based data collection, all

identifying information, such as names and email addresses, was kept in a separate database and used only to identify incentive recipients. For the paper-based data collection, consent forms were separated from survey packets upon receipt. These paper consent forms were stored separately from the survey data and were only utilized to identify those participants interested in the drawing. A minimum of identifying information was used to provide those participants who received an incentive (i.e., win the drawing) with their preferred gift card.

A preliminary survey was tested in order to estimate the length of time needed to complete the survey. The entire survey was completed in approximately 35 - 40 minutes. This estimated time was communicated to potential participants.

Data Analyses

Overall, preliminary analyses were conducted to determine the relative fit of the data to Ordinary Least Squares (OLS) assumptions. Preliminary analyses utilized the steps recommended by Tabachnick and Fidell (2007), including data screening and addressing missing data, examining the extent to which the data conformed with assumptions of normality, linearity, and homoscedasticity, and addressing issues with outliers and multicollinearity. In order to test the internal consistency of the survey items, Cronback's alpha coefficients were computed for each measure and relevant subscale. Means and standard deviations for all study measures are reported. Demographic information for participants is also reported. Please see Chapter Four for these results.

Main analyses examined the direct relationship between family beliefs and family adaptation through use of both simple and multiple regression analyses. Simple regression analyses were conducted to assess the relationships between the three family belief factors, optimism (i.e., LOT-R), control (i.e., HLCInt subscale), and mastery (i.e., SOC), and the one family outcome (i.e. FQOL). Additional exploratory regression analyses were conducted utilizing two additional control subscales (i.e., HLCExt and HLCP) to assess the relationship between these subscales and the outcome variable (i.e., FQOL). Finally, multiple regression analyses were conducted to assess the relationship between combinations of control subscales and the outcome variable (i.e., FQOL).

Main analyses also examined the extent to which family beliefs mediate the relationship between two family demand variables (i.e., uncertainty and perceived severity) and the family outcome (i.e., family quality of life). Correlational analyses were conducted to assess the relationships between study variables as a part of the preliminary analyses, but were also utilized in these main mediation analyses. Simple regression analyses were conducted to assess the relationship between the two family demand factors, perceived severity (i.e. PCQ) and uncertainty (i.e., PPUS), and the one family outcome (i.e., FQOL). Additional regression analyses were then conducted to establish mediation utilizing the product of coefficients method, as outlined by McKinnon and colleagues (2002) and Jose (2003). Specifically, a series of simple regressions were computed in which each of the family demands (i.e., PCQ and PPUS) were regressed upon the family beliefs (i.e., LOT-R and SOC). Then, a series of multiple regressions were computed in which family demands (i.e., PCQ and PPUS) and family

beliefs (i.e., LOT-R and SOC) were entered into regression equations simultaneously as IVs, and where FQOL was designated as the DV. Bivariate correlations indicated that the control subscales (i.e., HLCInt, HLCExt, and HLCP) did not have the statistically significant relationships with the IVs or DV necessary for mediation to exist, thus no additional analyses were conducted with these variables. Finally, the Sobel first-order approximation test (Sobel, 1982) was utilized to establish the statistical significance of each test for mediation.

Originally this study proposed to utilize the widely-used causal step approach to statistical mediation analysis suggested by Baron and Kenny (1986). However, after further outside consultation, the product of coefficients method was utilized instead. The main reason for this change in analysis procedure was the increase in power gained by using the product of coefficients method to mediation effects. The product of coefficients method is considered to be a more powerful method since it does not necessitate that the independent variable (IV) and dependent variable (DV) be significantly correlated with each other, unlike with the causal step approach (e.g., McKinnon et al., 2002; McKinnon, Fairchild, & Fritz, 2007). In cases in which the mediator is a "suppressor variable," or one in which it is a full (complete) mediator of the IV - DV relationship, the product of coefficients method will identify this relationship while the causal step approach may not (e.g., McKinnon et al., 2002; McKinnon, Fairchild, & Fritz, 2007).

CHAPTER 4

Results

This chapter begins with a description of the demographic and background variables of the sample. The chapter then describes the steps taken to screen the data and address missing data. Next, preliminary analyses of the study's measures, including the range, mean, standard deviation, and internal consistency reliabilities, are presented. This chapter then describes preliminary analyses used to address issues that might affect the main analyses, namely, assumptions of normality, linearity, and homoscedasticity; potential univariate and multivariate outliers; and potential issues with multicollinearity. Finally, the main analyses of this study, presented according to corresponding hypotheses, and their results are presented.

Demographic and Background Variables

The final sample for this study consisted of 207 parents or primary caregivers of children diagnosed with one of three autism spectrum disorders: Asperger's Syndrome, PDD-NOS, or Autism. Of the 207 total participants, 129 participated via paper survey and 78 participated via web-based survey. All participants noted their consent for participation in this study and included identifying information, kept separate from their survey responses, for inclusion in a volunteer random drawing. Separate examination of this identifying information noted no redundant information; that is, all participants participated only once in this study. Please see Tables 2 and 3 for a summary of demographic characteristics.

Table 2.

Participant Demographic and Background Variables (N=207)

Category	N	%	Category	N	%
Sex			*Family Income*		
Females	188	90.8%	$40,000 - $59,999	35	16.9%
Males	19	9.2%	Over $150,000	35	16.9%
			$60,000 - $79,999	33	15.9%
Race			$80,000 - $99,999	32	15.5%
White (Non-Hispanic)	190	91.8%	$100,000 - $124,999	32	15.5%
Asian or Asian –American	5	2.4%	$20,000 - $39,999	18	8.7%
Black or African-American	5	2.4%	$125,000 - $149,999	7	3.4%
Multiracial	3	1.4%	Under $20,000	6	2.9%
Hispanic or Latino	2	1.0%	Missing	9	4.3%
Missing	2	1.0%			
			Total Number of Children		
Relationship to child			2	96	46.4%
Biological Mother	177	85.5%	1	49	23.7%
Biological Father	18	8.7%	3	40	19.3%
Adoptive Mother	11	5.3%	4	13	6.3%
Stepfather	1	.5%	5	4	1.9%
			6	2	1.0%
Level of Education			8	2	1.0%
4 Year College/University	91	44%	Missing	1	.5%
Master's Degree	38	18.4%			
Some College	27	13%	*Number of Children diagnosed with ASD*		
Vocational, professional			1	188	90.8%
certificate, or associate degree	22	10.6%	2	16	7.7%
High School	19	9.2%	Missing	3	1.5%
Doctoral Degree	10	4.8%			
			Sex of Child diagnosed with ASD		
Marital Status			Male	167	80.7%
Married	172	83.1%	Female	39	18.8%
Divorced	15	7.2%	Missing	1	.5%
Separated	8	3.9%			
Domestic partner	5	2.4%	*Race of Child Diagnosed with ASD*		
Single	3	1.4%	White (Non-Hispanic)	188	90.8%
Widowed	3	1.4%	Black or African-American	5	2.4%
Missing	1	.5%	Asian or Asian-American	4	1.9%
			Hispanic or Latino	4	1.9%
Work Status			Multiracial	3	1.4%
FT work outside of home	71	34.3%	Middle Eastern	1	.5%
Stay at Home Caregiver	62	30.0%	Missing	2	1.0%
PT work outside of home	56	27.1%			
PT work from home	10	4.8%	*Specific Diagnosis of Child Diagnosed with ASD*		
FT work from home	4	1.9%	PDD-NOS	84	40.6%
Missing	4	1.9%	Autism	69	33.3%
			Asperger's Syndrome	54	26.1%

Table 3.
Participant Demographic and Background Variables, Continued

	N	*M*	Range
Participant Age	203	42.6	25 - 69
Child Diagnosed with an ASD Age	204	10.4	2 - 28
Age Child was Diagnosed	206	3.95	2 - 19
Total Hours of Services	206	28.52	0 - 146
Total Hours of Behavioral Services	124	11.11	1 - 72
Total Hours of Educational Services	188	22.45	1 - 73
Total Hours of Private Therapies	82	2.54	1 - 33
Total Hours of Adult-Focused Services	4	17.25	1 - 30
Total amount of CAMs attempted	207	2.20	0 - 23
Current amount of CAMs being used	207	1.28	0 - 13

The majority of participants (96%) noted that they currently reside in Pennsylvania. Nine participants provided out of state zip codes. Individual analysis of these nine

participants showed that six had children diagnosed with an ASD in residential school programs within Pennsylvania. The remaining three parents noted on their surveys either that they had recently moved from Pennsylvania or were a divorced spouse.

The average age of the participants who provided their age (N=203) was 42.6 years old, with participants ranging in age from 25 to 69 years old. Over ninety percent (90.8%) of study participants indicated their sex as female, while 9.2% indicated their sex as male. Of the participants who provided information regarding their race (N=205), participants identified their race in the following manner: 91.8% White, 2.4% Asian or Asian-American, 2.4% Black, African, or African-American, 1.4% Multiracial, 1% Hispanic or Latino. Participants noted their caregiver relationship as biological mother

(85.5%), biological father (8.7%), adoptive mother (5.3%), or step-father (.5%). While adoptive mother was not a provided relationship option, all 11 women who identified themselves as "non-biological caregivers" either directly emailed the principal investigator or wrote on their survey their desire that their relationship status as adoptive caregiver be recognized in that manner.

Of the participants who provided information regarding their marital status (N=206), the majority of participants (83.1%) indicated that they were married, with 7.2% divorced, 3.9% separated, 2.4% living with a domestic partner, 1.4% single, and 1.4% widowed. All participants provided information regarding their level of education, with the majority indicating "4 Year College/University" (44%), 18.4% responding "Master's Degree," 13% responding "some college," 10.6% responding "Vocational, professional certificate, or associate degree," 9.2% responding "High School," and 4.8% responding "Doctoral Degree." Of the 203 participants who provided information regarding their work status, 34.3% indicated that they work full time outside of the home, 30% are stay at home caregivers, 27.1% work part time outside of the home, 4.8% work part time from home, and 1.9% work full time from home. Of those who noted their family incomes (N=198), 16.9% reported a family income of $40,000-$59,999, 16.9% reported a family income of over $150,000, 15.9% reported a family income of $60,000-$79,999, 15.5% reported and income of $80,000-$99,999, 15.5% reported a family income of $100,000-$124,999, 8.7% reported a family income of $20,000-$39,999, 3.4% reported a family income of $125,000-$149,999, and 2.9% reported a family income of under $20,000.

Of the participants who provided information regarding the total number of children in their family (N=206), 46.4% had 2 children, 23.7% had 1 child, 19.3% had 3 children, 6.3% had 4 children, 1.9% had 5 children, 1% had 6 children, and 1% had 8 children. The majority of participants (90.8%) noted having only one child diagnosed with an ASD, while 7.7% noted having two children diagnosed with an ASD and 1.5% not providing a response to the question.

Overall, 204 participants provided information regarding their child's age, with 10.4 years old the average age of their children diagnosed with an ASD (with ages ranging from 2 years old to 28 years old). The mean age of diagnosis was 3.95 years old, with a range from 2 years old to 19 years old (N=206). Children's sex was reported as 80.7% male and 18.8% female (N=206). Of the participants who provided information regarding their child's race (N=205), participants identified their child's race in the following manner: 90.8% White; 2.4% Black, African, or African-American; 1.9% Asian or Asian-American; 1.9% Hispanic or Latino; 1.4% Multiracial; and .5% Middle Eastern. All participants noted their child's diagnosis, with 40.6% indicating PDD-NOS, 33.3% indicating Autism, and 26.1% indicating Asperger's Syndrome.

Finally, 206 participants provided information regarding the services and therapies their children were utilizing. Overall, participants reported that their children were receiving an average of 28.52 total hours of services per week, with the total amount of services ranging from 0 to 146 hours spread across educational services, behavioral services, private therapies, or adult-focused activities/therapies. Of the 206 participants, 188 participants noted that their children were receiving educational

services. The average amount of these educational services was reported to be 22.45 hours per week, with a range of 1 to 73 hours. Of the 206 participants who provided information regarding services, 124 participants noted that their children were receiving behavioral services. The average amount of these behavioral services was reported to be 11.11 hours per week, with a range of 1 to 72 hours. Additionally, 82 of the 206 participants indicated that their children were utilizing private therapies. The average amount of these private therapies was reported to be 2.54 hours per week, with a range of 1 to 33 hours. Finally, 4 participants indicated that their children were utilizing adult-focused services or therapies. The average amount of these adult-focused services or therapies was reported to be 17.25 hours per week, with a range of 1 to 30 hours.

Participants also provided information regarding the use of complementary or alternative (CAM) treatments with their children. CAMs were defined to participants as supplemental treatments beyond those they had already reported on (e.g., dietary restrictions, dietary supplements, medication, etc.). On average, participants reported having tried at some point in time a total of 2.20 different types of CAMs, with participants noting a range of having tried no CAMs to as many as 23 different types. Participants also reported currently using an average of 1.28 CAMs with their children, ranging from using no CAMs to using as many as 13 different types at the same time.

Data Screening and Addressing Missing Data

Utilizing the procedures outlined in Chapter Three, data was originally collected from a total of 221 participants. Prior to data analysis, the data file was screened to

ensure its accuracy. Screening consisted of both examining descriptive statistics for unusual scores as well as proofreading the original data set against the computerized data. No unusual scores were detected and any typos within the data set were corrected. Two records were deleted because the participant's child did not meet inclusion criteria (i.e., did not have a diagnosis of Asperger's Disorder, PDD-NOS, or Autism). Omitted demographic material did not prevent the inclusion or a data record as long as the child's diagnosis was designated.

Next, missing data was addressed through two separate procedures. First, if a data record was missing more than 10% of a specific measure, the record was deleted from the data set. Six records were identified as meeting or exceeding this criteria and were deleted from the data set. An additional six records collected through the web-based survey were deleted because of large amounts of missing data resulting from the participants' ending the survey prematurely. For the remaining records, 29 records were missing less than 10% of a specific measure. For these records, the missing data was addressed through means substitution. Specifically, each missing value was replaced by the participant's mean response for that specific measure. This resulted in a final data set consisting of 207 participants with complete measures.

Table 4.

Statistical Characteristics for Study Measures (N=207)

Construct	Variables	Instrument	Subscale	*M*	*SD*	Range	α
Family Adaptation							
	Family Quality of Life	Family Quality of Life Survey (FQOL)		94.11	16.27	44-125	.94
Family Beliefs							
	Optimism (Global)	Life Orientation Test – Revised (LOT-R)		20.07	4.46	6-30	.84
	Control (ASD-specific)	Multidimensional Health Locus of Control – Form C (MHLC-C)	Internal (HLCInt)	16.11	5.90	6-35	.81
			Chance (HLCExt)	14.91	5.83	6-36	.81
			Doctor/ Professional (HLCP)	12.14	3.20	3-18	.70
			Other People (HLCO)	11.37	2.95	3-18	.60
	Mastery (Global)	Orientation to Life Questionnaire, short form (SOC-13)		60.39	12.85	19-88	.85
Demand Factors							
	Uncertainty regarding individual's ASD	Parent Perception of Uncertainty Scale (PPUS)		85.81	15.94	50-135	.88
	Perceived severity of individual's ASD	Parental Concerns Questionnaire (PCQ)		30.68	7.52	15-52	.84

Preliminary Analyses – Measures

Preliminary analyses were conducted on all predictors, potential mediators, and criterion variables. Table 4 summarizes the range, mean, standard deviation, and internal consistency reliabilities (Cronbach Alphas) for all measures and relevant subscales used in this study.

Family Quality of Life (FQOL)

As noted in Chapter 3, the Family Quality of Life (FQOL) Survey was used to measure the variable of family quality of life. The Family Quality of Life Survey is a 25 item measure with total possible scores ranging from 25 to 125. Higher scores reflect greater levels of satisfaction with the family's quality of life (Beach Center on Disability, 2005). In this sample, scores ranged from 44 to 125, with a mean of 94.11 and a standard deviation of 16.27. Thus, as a whole, this sample indicated that they were generally satisfied with their family's quality of life. The internal consistency reliability for the total FQOL score was .94, which is slightly higher than the .88 internal consistency reliability reported by Hoffman and colleagues (2006).

Optimism (LOT-R)

As noted in Chapter 3, the Life Orientation Test – Revised (LOT-R) was used to measure the variable of optimism. The LOT-R is a six item measure with total possible scores ranging from 6 to 30. Higher scores reflect a more optimistic view (Carver & Scheier, 2003). In this sample, scores ranged from 6 to 30, with a mean of 20.07 and a standard deviation of 4.46. Thus, as a whole, this sample appears to have more optimistic than pessimistic views of life. The internal consistency reliability for the LOT-R was .84,

consistent with previously reported alphas (e.g., Carver & Scheier, 2003; Greenberg et al., 2004).

Control (MHLC-C)

As noted in Chapter 3, the Multidimensional Health Locus of Control – Form C (MHLC-C) was used to measure the variable of participants' beliefs of control specific to a family member's ASD. The MHLC-C is an 18 item measure that reflects four dimensions or subscales: 1) Internal health locus of control; 2) Chance health locus of control; 3) Doctors/Professionals (type of powerful others); and 4) Other People (type of powerful others). Higher scores on each scale reflect a greater attribution of control to that particular source (Wallston, Stein, & Smith, 1994).

Internal Health Locus of Control (HLCInt). This subscale is comprised of six questions, with possible scores ranging from 6 to 36. In this sample, scores on this subscale ranged from 6 to 35, with a mean of 16.11 and a standard deviation of 5.90. Thus, taken together, this sample attributed less control over their child's ASD to themselves. The internal consistency reliability for this subscale was .81, consistent with previously reported alpha ranges (Wallston, Stein, & Smith, 1994).

Chance Health Locus of Control (HLCExt). This subscale is comprised of six questions, with possible scores ranging from 6 to 36. In this sample, scores on this subscale ranged from 6 to 36, with a mean of 14.91 and a standard deviation of 5.83. As a whole, this sample attributed less control over their child's ASD to chance. The internal consistency reliability for this subscale was .81, consistent with previously reported alpha ranges (Wallston, Stein, & Smith, 1994).

Doctors/Professional Locus of Control (HLCP). This subscale is comprised of 3 questions, with possible scores ranging from 3 to 18. In this sample, scores on this subscale ranged from 3 to 18, with a mean of 12.14 and a standard deviation of 3.20. As a whole, this sample attributed slightly greater control over their child's ASD to professionals. The internal consistency reliability for this subscale was .70, low but still consistent with previously reported alpha ranges (Wallston, Stein, & Smith, 1994).

Other People Locus of Control (HLCO). This subscale is comprised of 3 questions, with possible scores ranging from 3 to 18. In this sample, scores on this subscale ranged from 3 to 18, with a mean of 11.37 and a standard deviation of 2.95. As a group, this sample was relatively neutral regarding the control over their child's ASD attributed to other people. The internal consistency reliability for this subscale was .60, much lower than previously reported alphas (Wallston, Stein, & Smith, 1994). As will be discussed in the following section, given the potential collinearity issues with this variable and the Doctors/Professional Locus of Control (HLCP) variable, as well its low internal reliability, this variable was left out of all remaining analyses.

Mastery (SOC)

As noted in Chapter 3, the short version of the Orientation to Life Questionnaire, also known as the Sense of Coherence Scale (SOC-13), was used to measure the variable of mastery beliefs. The SOC-13 is a thirteen item measure with possible scores ranging from 7 to 91. Higher scores reflect a greater sense of coherence, or mastery (Antonovsky, 1987). In this sample, scores ranged from 19 to 88, with a mean of 60.39 and a standard deviation of 12.85. As a group, this sample demonstrated a slightly

increased sense of coherence. The internal consistency reliability for this subscale was .85, consistent with previously reported alpha ranges (Erikson & Lindstrom, 2005).

Uncertainty (PPUS)

As noted in Chapter 3, the Parent Perception of Uncertainty Scale (PPUS) was selected to measure the level of uncertainty parents experience regarding their child's ASD. The PPUS is a 31 item measure with possible scores ranging from 31 to 155. Higher scores indicate greater levels of uncertainty (Mishel, 1997). In this sample, scores ranged from 50 to 135, with a mean of 85.81 and a standard deviation of 15.94. As a group, this sample reported neutral levels of uncertainty. The internal consistency reliability for the total scale was .88, consistent with previously reported alphas (Carpentier, Mullins, Chaney, & Wagner, 2006; Mishel, 1983).

Severity (PCQ)

As noted in Chapter 3, the Parental Concerns Questionnaire (PCQ) was selected to measure the level of perceived severity of the child's ASD specific and associated psychiatric symptomatology. The PCQ is a 13 item measure with possible scores ranging from 13 to 52. Higher scores reflect greater level of perceived severity (McGrew et al., 2007). In this sample, scores ranged from 15 to 52, with a mean of 30.68 and a standard deviation of 7.52. As a group, this sample reported that their children demonstrated on average mild to moderate perceived severity. Individual areas that scored highest in perceived severity were Social Interactions, Attention Span, and Anxiety, while individual areas that scored lowest in perceived severity were Self-Injurious Behaviors and Aggression. The internal consistency reliability for this scale was .84, consistent

with previously reported alpha ranges (McGrew et al., 2007). Means and standard deviations for each item are reported in Table 5.

Table 5.
Summary of Means and Standard Deviations for PCQ Items

Item	*M*	*SD*
1. Language use and understanding	2.61	1.08
2. Compulsive behaviors	2.43	.98
3. Anxiety	2.71	.89
4. Sensory issues	2.51	.94
5. Sleep disturbance	2.03	1.09
6. Aggression	1.87	.97
7. Hyperactivity	2.42	1.05
8. Attention span	2.85	.89
9. Mood swings	2.25	1.00
10. Eating habits	2.34	1.13
11. Social interactions	3.00	.95
12. Self-stimulatory and repetitive behaviors	2.23	1.06
13. Self-injurious behavior	1.43	.75

Goodness of Fit to OLS Assumptions

The main analyses utilized in this study include Ordinary Least Squares (OLS) simple and multiple regression analyses. Underlying these OLS analyses are assumptions that must not be violated to ensure that the statistical measures are a good fit for the given data. OLS assumptions include: 1) the independent variables are fixed and values for those variables can be replicated; 2) the independent variables are measured without error; 3) and the relationship between the independent variables and the criterion variable is linear. Other assumptions that exist for OLS regression analyses concern the distribution of the residuals, including: 1) the residuals between individual cases are uncorrelated, 2) the residuals have homoscedasticity (i.e., residuals have an equal

variance throughout the range of the predictor and that the distribution of the residuals is roughly normal), and 3) the residuals are not correlated with the predictor. Thus, the following reviews the steps taken to examine the extent to which the data is best fit by the model.

The data set was examined for how well the distributions of each variable fit the assumptions of normality. Statistical values for skewness and kurtosis for each variable were calculated. Acceptable values for both skewness and kurtosis fall within the range of ±1; all variables fit this criterion.

This data set was also examined for univariate outliers using both statistical and graphical procedures. For continuous variables, univariate outliers are cases which have very large z scores (i.e., in excess of 3.29 with $p<.001$, two-tailed), or other standardized scores, on one or more variables and are disconnected from the other z scores in the data set (Tabachnick & Fidell, 2007). Z scores were computed for all of the measures utilized in this study. Using the Tabachnick and Fidell criterion, one case was identified as a potential univariate outlier (i.e., z score > 3.29). Box plots and histograms were generated to provide graphical representation of the data set. While this one case was distinguishable on both graphs, it did not appear to be dramatically unattached to the rest of the data set, but rather on the outskirts of a spread of data points.

Given the potential univariate outlier's proximity to other data points, transformations were attempted to see if it improved the overall distribution and limited the influence of the potential outlier. Statistical and graphical representations were computed again utilizing the transformed variables. No improvement was visually noted

on the histograms, with the calculated values for skewness and kurtosis either remaining the same or worsening. As such, the transformations were discarded and further statistics were based upon the original non-transformed data set. As a final examination of the impact of the one potential univariate outlier, all statistics and graphs were recomputed without its inclusion. No noticeable graphical changes or significant statistical changes were noted. Since Tabachnick and Fidell (2007) note that, as sample size increases, some z scores in excess of 3.29 are expected, the potential univariate outlier was deemed reflective of the population currently under study and was retained for all data analyses.

In addition, the data set was examined for the presence of multivariate outliers, as suggested by Tabachnick and Fidell (2007). According to Tabachnick and Fidell (2007), multivariate outliers are cases that lie some distance from other cases in multivariate space (Tabachnick & Fidell, 2007). Mahalanobis distance is one conservative measure of that multivariate distance and utilizes X^2 in the evaluation of potential multivariate outliers. Mahalanobis values for all variables were generated using case id as the dummy dependent variable, as recommended by Tabachnick and Fidell (2007). Two potential multivariate outliers were identified through this recommended procedure; that is, two variables exceeded the Chi-square value for 8 variables (ie., 26.125) at $p<.001$. Pre-analysis statistics were again computed without these two cases included, with no discernable difference in either the resulting graphs or statistics noted. Since little was lost or gained by their presence, the decision was made to retain these two cases for all further analyses.

Given the statistical methods used to test this study's hypotheses, the data set was also examined for multicollinearity. A Pearson product moment correlation matrix was produced to examine the bivariate correlations between this study's predictors and criterion (see Table 4). If a bivariate correlations are too high (i.e., a bivariate correlation of above ±.90), collinearity may be evident (Tabachnick & Fidell, 2007). As Table 6 shows, this criterion was not met, indicating no collinearity issues.

Table 6.
Correlations among Study Variables

	Measure	1.	2.	3.	4.	5.	6.	7.	8.	9.
1.	FQOL Total	----								
2	LOT-R Total	.352**	----							
3.	HLC Internal	-.035	-.103	----						
4.	HLC Chance	-.013	-.179*	.168*	----					
5.	HLC Professional	.208**	.109	.064	-.049	----				
6.	HLC Other	.023	.006	.272**	.082	.336**	----			
7.	SOC Total	.457**	.595**	-.181**	-.153*	.059	-.096	----		
8.	PCQ Total	-.423**	-.161*	-.022	.040	-.115	-.081	-.265**	----	
9.	PPUS Total	-.478**	-.258**	.028	.218**	-.111	.044	-.417**	.503**	----

* $p<.05$ **$p<.01$

In addition, multicollinearity statistics were produced to examine the multivariate correlations (see Table 7). As described by Tabachnick and Fidell (2007), if one of the tested dimensions has a Condition Index greater than 30, and more than one Variance Proportion is greater than .50, then multicollinearity may be an issue. As Table 7 shows,

there are two instances in which multicollinearity may be an issue; that is, in dimension 8, PCQ and PPUS appear to have an issue with collinearity, while in dimension 6, HLCP and HLCO appear to have an issue. Tabachnick and Fidell (2007) suggest several options to address these multicollinearity issues. One option, if the goal of analysis is prediction, is that the multicollinearity can be ignored (Tabachnick & Fidell, 2007). Another option is to delete the variable with the highest variance proportion. Since the PCQ and PPUS will be kept separate in the main prediction analyses, the decision was made to retain these variables. However, the decision was made to discard the HLCO variable, the variable with the highest variance proportion, and retain only the HLCP in the remaining analyses. This decision was made based upon the following reasons: 1) the HLCO and HLCP subscales have a similar theoretical definition, and 2) the internal consistency reliability for the HLCO was much lower than previously reported.

Table 7.
*Multicollinearity Diagnostics**

				Variance Proportions									
Model	**Dimension**	**Eigenvalue**	**Condition Index**	**(Constant)**	**FQOL Total**	**LOT-R Total**	**HLC Internal**	**HLC Chance**	**HLC Prof.**	**HLC Other**	**SOC Total**	**PCQ Total**	**PPUS Total**
1	1	9.479	1.000	.00	.00	.00	.00	.00	.00	.00	.00	.00	.00
	2	.150	7.961	.00	.01	.03	.10	.35	.01	.00	.02	.00	.00
	3	.110	9.294	.00	.00	.00	.55	.22	.01	.03	.00	.02	.01
	4	9.080E-02	10.217	.00	.01	.01	.00	.30	.00	.00	.01	.19	.04
	5	6.843E-02	11.770	.00	.00	.03	.24	.00	.31	.20	.03	.01	.00
	6	3.974E-02	15.445	.00	.00	.01	.06	.00	.55	.67	.00	.01	.00
	7	2.263E-02	20.465	.01	.32	.56	.01	.10	.07	.00	.00	.02	.02
	8	2.010E-02	21.718	.00	.00	.08	.00	.03	.00	.07	.06	.62	.51
	9	1.536E-02	24.845	.00	.30	.28	.01	.00	.03	.00	.77	.06	.05
	10	4.271E-03	47.112	.98	.34	.00	.04	.00	.01	.02	.10	.08	.37

* Dependent variable: case id

Finally, fit analyses were completed after each main analysis was conducted. Specifically, to ensure that the regression models did not violate the OLS assumptions, after each regression analysis, the studentized residual histograms, normal probability plots and residual plots were generated and examined. All plots appeared as would be expected and did not appear to violate these assumptions.

Preliminary and Goodness of Fit Analyses – Summary

The recommended steps (Tabachnick & Fidell, 2007) regarding data screening for OLS (Ordinary Least Squares) assumptions were completed. The data set was proofread and missing data was addressed using minimal deletion of cases and mean substitution. The data set conformed with assumptions of normality, linearity and homoscedasticity. One univariate outlier was detected, but since neither transformations nor deletion from the data set dramatically changed preliminary analyses, the univariate outlier was retained. Two multivariate outliers were detected, but since deletion from the data set did not dramatically change the preliminary analyses, these multivariate outliers were retained. Finally, while bivariate correlations did not indicate collinearity issues, multicollinearity statistics indicated two potential issues with multicollinearity. Following the suggestions of Tabachnick and Fidell (2007), the potential multicollinearity issue arising from the PCQ and PPUS scales was ignored, while the potential multicollinearity issue arising from the HLCP and HLCO subscales was addressed by removing the HLCO subscale from subsequent analyses.

Overall, the data from the study measures were normally distributed and demonstrated adequate standard deviations reflecting that a sufficient range of responses had been sampled. All measures and subscales demonstrated internal consistency reliabilities consistent with previous reports, except for the HLCO subscale. As noted above, this subscale was discarded.

Main Analyses by Research Question

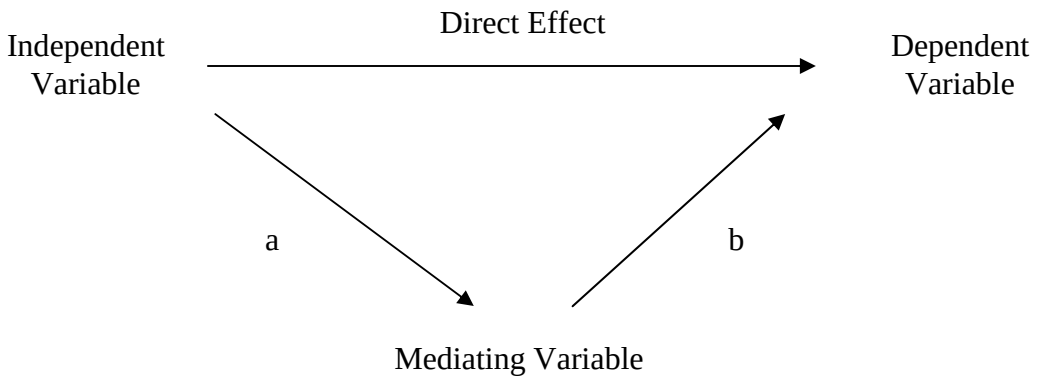
The following summarizes the analyses conducted to test the hypotheses proposed in Chapter 2. For hypotheses utilizing simple regression, the amount of variance accounted for (R^2) and the relative strength of the relationship between variables (Standardized Betas) is reported. Standardized Betas (β) are used to compare variables that are measured in different units, since they represent regression coefficients that have taken into consideration the standard deviation of the variables.

Several hypotheses in this study test for mediation. While it was initially planned that the causal steps suggested by Baron and Kenny (1986) were to be used in these analyses, MacKinnon and colleagues (MacKinnon et al., 2002; MacKinnon, Fairchild, & Fritz, 2007) have recommended the use of other methods to assess mediation, such as using the product of coefficients method, and detect the relative significance of the mediation effect, including the commonly used Sobel first-order approximation test (Sobel, 1982).

Figure 4 graphically depicts the basic mediation model. The combination of using the product of coefficients method with Sobel's test can statistically examine both

if a variable is a mediator and whether or not statistically significant mediation has occurred. This method of computing the indirect effect (i.e., the effect of the IV on the DV through the mediator) and its significance is based upon the product of the coefficients for the IV – Mediator portion of the indirect effect (labeled 'a' in Figure 4), the Mediator – DV portion of the indirect effect (labeled 'b' in Figure 4), and the overall indirect effect (i.e., a*b, or the product of a and b). Three separate statistical analyses are used in the product of coefficients method. First, correlations are computed among the IV, Mediator, and DV. Second, a regression is computed in which the mediator is designated as the DV and the IV is designated as the IV of the regression equation. Lastly, a multiple regression is computed in which the IV and Mediator are entered into the regression simultaneously as the IVs and the DV is designated as the DV in the regression equation. The resulting information from these three analyses, namely the correlations, unstandardized regression coefficients (B), standard errors (se), and standardized regression coefficients (Betas, or β) are then used in Sobel's mathematical equation to examine the presence and significance of mediation. While several tools exist to help with this final computation, for this study, Dr. Paul Jose's MedGraph program was utilized to generate the final Sobel test results (Jose, 2003).

Figure 4. *Basic Mediation Model*



a*b = indirect effect

The use of the product of coefficients method, rather than the traditional causal step method (Baron & Kenny, 1986), is recommend because of issues with power and type I error rates (McKinnon et al., 2002; McKinnon, Fairchild, & Fritz, 2007). In the traditional casual step method (Baron & Kenny, 1986), four steps are used to determine mediation. These include establishing that: 1) a significant relationship exist between the IV and the DV; 2) a significant relationship exists between the IV and hypothesized mediating variable; 3) a significant relationship exists between the hypothesized mediating variable and the DV when both the IV and hypothesized mediating variable are predictors of the DV; and 4) the coefficient relating the IV to the DV must have a larger absolute value than the coefficient relating the IV to the DV in the regression equation that has both the IV and hypothesized mediating variable predicting the DV (McKinnon, Fairchild, & Fritz, 2007).

The product of the coefficients method differs from the causal step method in that it does not require that the IV and DV have a significant relationship (MacKinnon, Fairchild, & Fritz, 2007). This main difference is thought to be the essence of the causal step method having less power to detect mediated effects as compared to other approaches, as demonstrated in a simulation study of 14 approaches to assessing mediate effects (MacKinnon et al., 2002). For example, in cases in which the mediator is a "suppressor variable," or one in which it is a full (complete) mediator of the IV - DV relationship, the product of coefficients method will identify this relationship while the causal step approach may not. Fritz and MacKinnon (2007) demonstrated that, to approximate the same power that the product of coefficients method has, the causal step method would require extremely large samples.

In this study, the Sobel's test is used in conjunction with the product of coefficients method to indicate whether or not significant mediation occurred. In doing so, the product of coefficients is divided by the standard error of the product and the resulting ratio is then compared to a standard normal distribution (MacKinnon, Fairchild, & Fritz, 2007). One disadvantage of utilizing Sobel's test is that it is sensitive to issues of normality. However, with normality assumptions intact, it is considered to be a better choice in examining mediation (both partial and full mediation) than the traditional causal step method without the test for significance (MacKinnon et al., 2002). Consequentially, all tests for mediation in this study utilized the combination of the product of coefficients method with Sobel's test.

General Hypothesis 1

This hypothesis stated that family members' beliefs significantly predict family adaptation. To test this general hypothesis, three specific hypotheses were proposed. These hypotheses and the resulting analyses follow.

Hypothesis 1a. This hypothesis stated that the participant's level of optimism (LOT-R) significantly predicts the family's quality of life (FQOL). Specifically, the greater the level of optimism, the greater the participants' satisfaction with their family's quality of life. A simple regression was used to test this hypothesis, using optimism (LOT-R) as the predictor and family quality of life (FQOL) as the criterion. Participants' level of optimism predicted 12.4% of the variance in family quality of life, which was statistically significant (R^2=.124, p<.05). Thus, the hypothesis that greater levels of optimism predict greater satisfaction with the family's quality of life was supported.

Hypothesis 1b. This hypothesis stated that the participants' health related locus of control (HLC) significantly predicts the family's quality of life (FQOL). To test this hypothesis, a simple regression was performed utilizing one subscale of health locus of control, the internal subscale (HLCInt), as the predictor and family quality of life (FQOL) as the criterion. Using this variable, it was expected that, as participants' internal health locus of control increased, so too would their satisfaction with their family's quality of life. Support for this hypothesis was not found; participant's internal health locus of control (HLCInt) did not predict a statistically significant portion of the variance in family quality of life (R^2=.001, p<.05). Further exploratory regressions were performed using the chance health related locus of control (HLCExt) and professional health related

locus of control (HLCP) subscales. Chance health related locus of control was found to not be predictive of the family's quality of life (R^2=.000, p<.05). Professional health related locus of control (HLCP), however, was found to predict 4.3% of the variance in family quality of life (FQOL), which was statistically significant (R^2=.043, p<.05).

A second part of this hypothesis stated that the combination of high internal and high external health locus of control would predict greater satisfaction with the family's quality of life than the combination of low internal and low external health locus of control. Since both chance locus of control and professional locus of control are considered to be aspects of external locus of control, two separate regressions were completed. First, a multiple regression was conducted in which the internal health locus of control (HLCInt) subscale and the chance locus of control (HLCExt) subscale were simultaneously entered as the predictors and family quality of life (FQOL) as the criterion. The combination of both internal health locus of control (HLCInt) and external health locus of control (HLCExt) was found to not be a significant predictor of family quality of life (FQOL) (R^2=.001, p<.05). Second, the internal health locus of control (HLCInt) subscale and the Professional health locus of control (HLCP) subscale were simultaneously entered as the predictors and family quality of life (FQOL) as the criterion. The combination of internal health locus of control (HLCInt) and professional health locus of control (HLCP) was found to predict 4.5% of the variance in family quality of life (FQOL), which was statistically significant (R^2=.045, p<.05).

Hypothesis 1c. This hypothesis stated that the participant's sense of coherence (SOC) significantly predicts the family's quality of life (FQOL). Specifically, the greater

the level of sense of coherence, the greater the participant's satisfaction with their family's quality of life. A simple regression was used to test this hypothesis, using sense of coherence (SOC) as the predictor and family quality of life (FQOL) as the criterion. Participants' sense of coherence predicted 20.1% of the variance in family quality of life, which was statistically significant (R^2=.209, p<.05). Thus, the hypothesis that greater levels of sense of coherence predict greater satisfaction with the family's quality of life was supported.

Overall, Hypothesis 1 was partially confirmed. Both level of optimism and sense of coherence were found to be significant positive predictors of family quality of life. Health locus of control, however, demonstrated mixed results. The hypothesis that internal health locus of control would positively predict family quality of life was not supported. The relationship between family quality of life and other aspects of health locus of control, that is health locus of control related to chance and related to professionals, were subsequently explored. While chance health locus of control was not found to be predictive of family quality of life, professional health locus of control was found to be significant positive predictor of family quality of life. The predictive power of the combination of internal health locus of control and external health locus of control was also examined. While the combination of internal health locus of control and chance health locus of control was found to be not significant, the combination of internal health locus of control and professional locus of control was found to be a significant positive predictor of family quality of life, though not to a much greater extent than professional

health locus of control by itself. Table 8 presents a summary of the regression results for Hypothesis 1.

Table 8.
Simple Regression Results for Family Members' Beliefs

Variable	R^2	β	*p*
1. Optimism (LOT-R)	.124	.352	<.05
2. Internal Health Locus of Control (HLCInt)	.001	-.035	n/a
3. Chance Health Locus of Control (HLCExt)	.000	-.013	n/a
4. Professional Health Locus of Control (HLCP)	.043	.208	<.05
5. Internal Health Locus of Control * Chance Health Locus of Control (HLCInt * HLCExt)	.001	-.008	n/a
6. Internal Health Locus of Control * Professional Health Locus of Control (HLCInt * HLCP)	.045	.211	<.05
7. Sense of Coherence (SOC)	.209	.457	<.05

General Hypothesis 2

This hypothesis stated that each of the family members' beliefs under consideration in this study (i.e., optimism, control, and mastery) act as mediators between the perceived severity (PCQ) of a child's ASD and the family's quality of life (FQOL). To test this general hypothesis, one specific hypothesis was proposed to explore the relationship between level of perceived severity and family quality of life. Additionally, three specific hypotheses were proposed, each using perceived severity (PCQ) as the IV

and family quality of life (FQOL) as the DV, with separate analyses for each potential mediator: optimism (LOT-R), control (HLCInt, HLCExt, HLCP), and sense of coherence (SOC).

Hypothesis 2a. This hypothesis stated that perceived severity (PCQ) significantly and negatively predicts family quality of life (FQOL). Specifically, as the perceived severity level of the child's ASD increases, the participants' satisfaction with their family's quality of life decreases. A simple regression was used to test this hypothesis, using perceived severity (PCQ) as the predictor and family quality of life (FQOL) as the criterion. Perceived severity predicted 17.9% of the variance in family quality of life, which was statistically significant (R^2=.179; β=-.423; p<.05). Thus, the hypothesis that greater levels of perceived severity predict lower satisfaction with families' quality of life was supported.

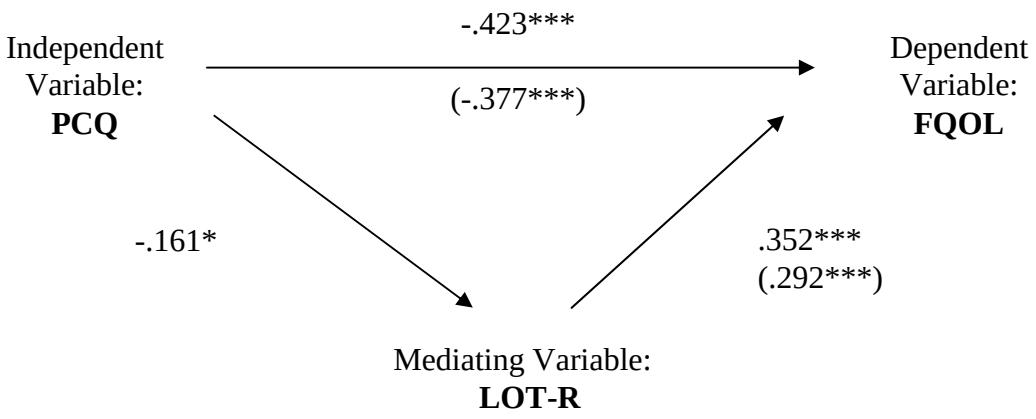
Hypothesis 2b. This hypothesis stated that optimism (LOT-R) mediates the relationship between level of perceived severity (PCQ) and family quality of life (FQOL). To test this hypothesis, the steps described previously were taken. First, correlations among perceived severity (PCQ), optimism (LOT-R), and family quality of life (FQOL) were identified from the previously computed Pearson product moment correlation matrix (please see Table 6). Next, a regression analysis was computed in which level of perceived severity (PCQ) was the IV and optimism (LOT-R) was the DV. Finally, a regression analysis was computed in which level of perceived severity (PCQ) and optimism (LOT-R) were entered in simultaneously as the IVs and family quality of life (FQOL) was the DV.

Table 9. *Regression Results with PCQ as IV and LOT-R as Mediator*

	IV	DV	B	Se	β
1.	PCQ	LOT-R	-.09525	.041	-.161
2.	PCQ	FQOL	---	---	-.377
	LOT-R		1.066	.222	.292

Table 9 provides relevant regression results used in calculating mediation and significance. Sobel's test was performed, with the results indicating that optimism (LOT-R) significantly mediates the relationship between perceived severity (PCQ) and family quality of life (FQOL) (Sobel z value = -2.0913; p=.037). That is, the association between level of perceived severity and family quality of life has been significantly reduced (i.e., correlations change from -.423 to -.377) by the inclusion of optimism in the second regression equation. It is important to note, however, that even with the addition of optimism as a mediator, the correlation between level of perceived severity and family quality of life is still significant ($\beta = -.377$, $p<.001$), thus indicating that partial, rather than full, mediation has occurred. The results of the mediation analysis, including original and modified correlations, are presented in Figure 5.

Figure 5. *Direct and Mediation Effect with PCQ as IV and LOT-R as Mediator*



* $p<.05$ *** $p<.001$

Hypothesis 2c. This hypothesis stated that control beliefs (i.e., HLCInt, HLCExt, or HLCP) mediate the relationship between perceived severity (PCQ) and family quality of life (FQOL). Prior to testing this hypothesis, the correlations among these variables were examined. According to MacKinnon, Fairchild, and Fritz (2007), two main correlations between the IV, Mediator, and DV (i.e., correlation between IV – Mediator and Mediator – DV) must be statistically significant for mediation to exist. Therefore, following this criterion, internal health locus of control (HLCInt) and chance health locus of control (HLCExt) could not be mediators between perceived severity (PCQ) and family quality of life (FQOL), since they are not significantly correlated to family quality of life (FQOL). In addition, while professional health locus of control (HLCP) does have a significant correlation with family quality of life (FQOL), it does not significantly

correlate with perceived severity (PCQ). Therefore, professional health locus of control (HLCP) could not be a mediator between perceived severity (PCQ) and family quality of life (FQOL).

Hypothesis 2d. This hypothesis stated that sense of coherence (SOC) mediates the relationship between perceived severity (PCQ) and family quality of life (FQOL). To test this hypothesis, the steps described previously were taken. First, correlations among perceived severity (PCQ), sense of coherence (SOC), and family quality of life (FQOL) were identified from the previously computed Pearson product moment correlation matrix (please see Table 6). Next, a regression analysis was computed in which perceived severity (PCQ) was the IV and sense of coherence (SOC) was the DV. Finally, a regression analysis was computed in which perceived severity (PCQ) and sense of coherence (SOC) were entered in simultaneously as the IVs and family quality of life (FQOL) was the DV.

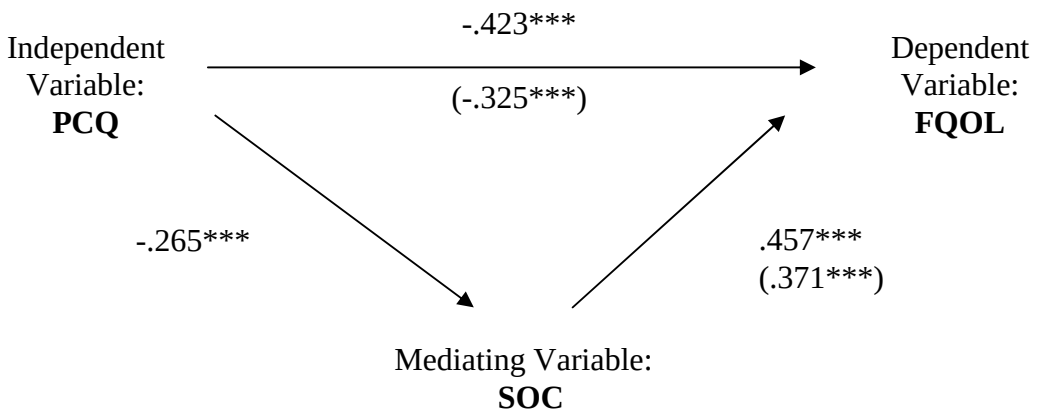
Table 10.
Regression Results with PCQ as IV and SOC as Mediator

	IV	DV	B	Se	β
1.	PCQ	SOC	-.452	.115	-.265
2.	PCQ	FQOL	---	---	-.325
	SOC		.470	.076	.371

Table 10 provides relevant regression results used in calculating mediation and significance. Sobel's test was performed, with the results indicating that sense of coherence (SOC) significantly mediates the relationship between perceived severity (PCQ) and family quality of life (FQOL) (Sobel z value = -3.3172; $p<.001$). That is, the

association between level of perceived severity and family quality of life has been significantly reduced (i.e., correlations change from -.423 to -.325) by the inclusion of sense of coherence in the second regression equation. It is important to note, however, that even with the addition of sense of coherence as a mediator, the correlation between perceived severity and family quality of life is still significant ($\beta = -.325$, $p<.001$), thus indicating that partial, rather than full, mediation has occurred. The results of the mediation analysis, including original and modified correlations, are presented in Figure 6.

Figure 6. *Direct and Mediation Effect with PCQ as IV and SOC as Mediator*



*** $p<.001$

Overall, Hypothesis 2 was partially confirmed. The perceived severity of an individual's ASD was found to be a significant negative predictor of family quality of life. Both optimism and sense of coherence were found to be significant partial mediators of the relationship between perceived severity of a child's ASD and the

family's quality of life. All three subscales of health locus of control, however, were not found to mediate the relationship between perceived severity of a child's ASD and family quality of life.

General Hypothesis 3

This hypothesis stated that each of the family members' beliefs under consideration in this study (i.e., optimism, control, and mastery) act as mediators between the uncertainty related to a child's ASD (PPUS) and the family's quality of life (FQOL). To test this general hypothesis, one specific hypothesis was proposed to explore the relationship between uncertainty and family quality of life. Additionally, three specific hypotheses were proposed, each using uncertainty (PPUS) as the IV and family quality of life (FQOL) as the DV, with separate analyses for each potential mediator: optimism (LOT-R), control (HLCInt, HLCExt, HLCP), and sense of coherence (SOC). As with hypotheses 2b-2d, the Sobel first-order approximation (Sobel, 1982) was utilized to test the significance of the potential mediation relationships. These specific hypotheses and resulting analyses follow.

Hypothesis 3a. This hypothesis stated that uncertainty (PPUS) significantly and negatively predicts family quality of life (FQOL). Specifically, as the level of uncertainty regarding the child's ASD increases, the participant's satisfaction with their family's quality of life decreases. A simple regression was used to test this hypothesis, using uncertainty (PPUS) as the predictor and family quality of life (FQOL) as the criterion. Uncertainty predicted 22.8% of the variance in family quality of life, which was statistically significant (R^2=.228; β= -.478; p<.05). Thus, the hypothesis that greater

levels of uncertainty predict lower satisfaction with the family's quality of life was supported.

Hypothesis 3b. This hypothesis stated that optimism (LOT-R) mediates the relationship between uncertainty (PPUS) and family quality of life (FQOL). To test this hypothesis, the steps described previously were taken. First, correlations among uncertainty (PPUS), optimism (LOT-R), and family quality of life (FQOL) were identified from the previously computed Pearson product moment correlation matrix (please see Table 6). Next, a regression analysis was computed in which uncertainty (PPUS) was the IV and optimism (LOT-R) was the DV. Finally, a regression analysis was computed in which uncertainty (PPUS) and optimism (LOT-R) were entered in simultaneously as the IVs and family quality of life (FQOL) was the DV.

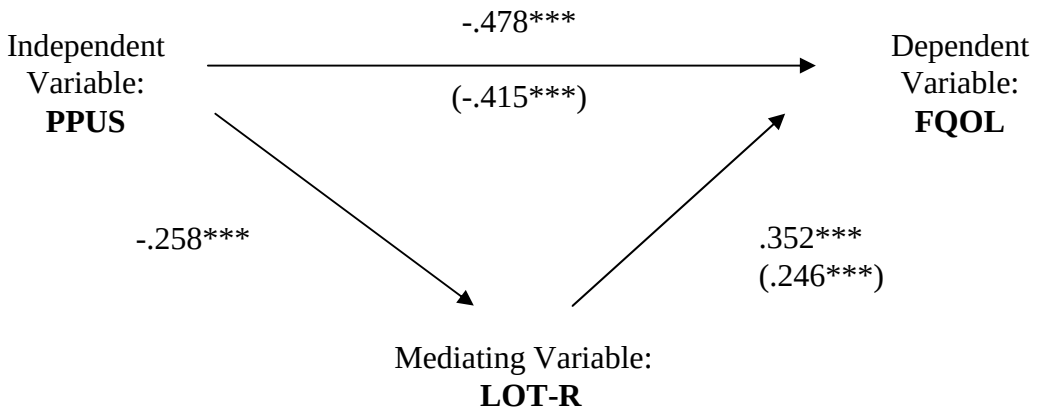
Table 11.
Regression Results with PPUS as IV and LOT-R as Mediator

	IV	DV	B	Se	β
1.	PPUS	LOT-R	-.07204	.019	-.258
2.	PPUS	FQOL	---	---	-.415
	LOT-R		.897	.224	.246

Table 11 provides relevant regression results used in calculating mediation and significance. Sobel's test was performed, with the results indicating that optimism (LOT-R) significantly mediates the relationship between uncertainty (PPUS) and family quality of life (FQOL) (Sobel z value = -2.7532; p=.006). That is, the association between uncertainty and family quality of life has been significantly reduced (i.e., correlations change from -.478 to -.415) by the inclusion of optimism in the second regression

equation. It is important to note, however, that even with the addition of optimism as a mediator, the correlation between uncertainty and family quality of life is still significant ($\beta = -.415$, $p<.001$), thus indicating that partial, rather than full, mediation has occurred. The results of the mediation analysis, including original and modified correlations, are presented in Figure 7.

Figure 7. *Direct and Mediation Effect with PPUS as IV and LOT-R as Mediator*



*** $p<.001$

Hypothesis 3c. This hypothesis stated that control beliefs (i.e., HLCInt, HLCExt, or HLCP) mediate the relationship between uncertainty (PPUS) and family quality of life (FQOL). As with Hypothesis 2c, prior to testing this hypothesis the correlations among these variables were examined for significance. Again, since internal health locus of control (HLCInt) and chance health locus of control (HLCExt) are not significantly correlated to family quality of life (FQOL), they could not be mediators between uncertainty (PPUS) and family quality of life (FQOL). In addition, while professional

health locus of control (HLCP) does have a significant correlation with family quality of life (FQOL), it does not significantly correlate with uncertainty (PPUS). Therefore, professional health locus of control (HLCP) could not be a mediator between uncertainty (PPUS) and family quality of life (FQOL).

Hypothesis 3d. This hypothesis stated that sense of coherence (SOC) mediates the relationship between uncertainty (PPUS) and family quality of life (FQOL). To test this hypothesis, the steps described previously were taken. First, correlations among uncertainty (PPUS), sense of coherence (SOC), and family quality of life (FQOL) were identified from the previously computed Pearson product moment correlation matrix (please see Table 6). Next, a regression analysis was computed in which uncertainty (PPUS) was the IV and sense of coherence (SOC) was the DV. Finally, a regression analysis was computed in which uncertainty (PPUS) and sense of coherence (SOC) were entered in simultaneously as the IVs and family quality of life (FQOL) was the DV.

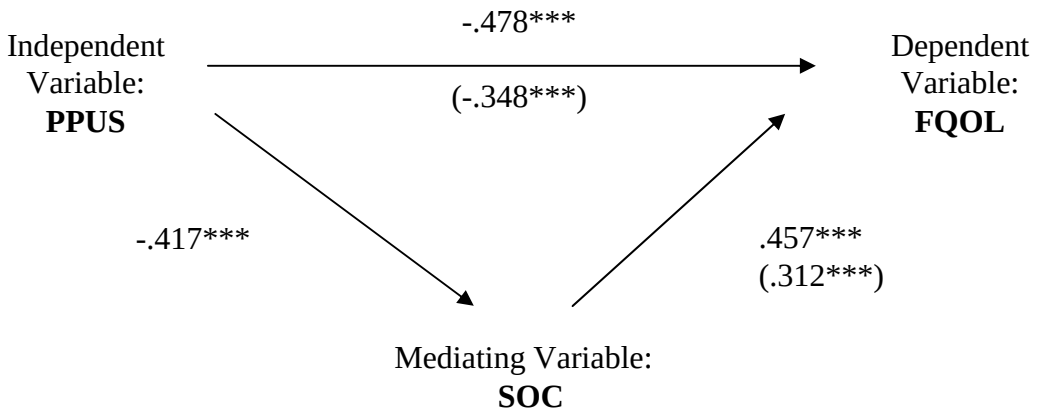
Table 12.
Regression Results with PPUS as IV and SOC as Mediator

	IV	DV	B	Se	β
1.	PPUS	SOC	-.336	.051	-.417
2.	PPUS	FQOL	---	---	-.348
	SOC		.395	.081	.312

Table 12 provides relevant regression results used in calculating mediation and significance. Sobel's test was performed, with the results indicating that sense of coherence (SOC) significantly mediates the relationship between uncertainty (PPUS) and family quality of life (FQOL) (Sobel z value = -3.9196; $p<.001$). That is, the association

between uncertainty and family quality of life has been significantly reduced (i.e., correlations change from -.478 to -.348) by the inclusion of sense of coherence in the second regression equation. It is important to note, however, that even with the addition of sense of coherence as a mediator, the correlation between uncertainty and family quality of life is still significant (β= -.348, p<.001), thus indicating that partial, rather than full, mediation has occurred. The results of the mediation analysis, including original and modified correlations, are presented in Figure 8.

Figure 8. *Direct and Mediation Effect with PPUS as IV and SOC as Mediator*



*** p<.001

Overall, Hypothesis 3 was partially confirmed. The uncertainty regarding a child's ASD was found to be a significant negative predictor of family quality of life. Both optimism and sense of coherence were found to be significant partial mediators of the relationship between uncertainty regarding a child's ASD and the family's quality of

life. All three subscales of health locus of control, however, were found to not mediate the relationship between level of perceived severity of a child's ASD and family quality of life.

Summary of Results

In summary, the results of this study indicate that, taken separately, several factors significantly predict participants' level of satisfaction with their family's quality of life. First, factors such as the perceived severity of an individual's ASD and the uncertainty regarding the individual's ASD significantly, and negatively, influence the family's quality of life. In addition, several beliefs that parents or other primary caregivers hold, including dispositional optimism, sense of coherence, and attributions of professional's level of control over the individual's ASD, significantly, and positively, influence the family's quality of life.

The results of this study further indicate that two factors can also act as mediators. Specifically, dispositional optimism and sense of coherence were found to be significant partial mediators of two relationships: 1) the relationship between the perceived severity of an individual's ASD and the family's quality of life, and 2) the relationship between the uncertainty regarding the child's ASD and the family's quality of life.

This study did not find support for the hypothesized relationship of health locus of control with family quality of life. That is, internal health locus of control was not found to be a significant predictor of family quality of life. Exploratory analyses also indicated that chance health locus of control also was not a significant predictor of family quality

of life. In addition, all three aspects of health locus of control (i.e., internal, chance, and professional) were found to not mediate the relationship between either the perceived severity of an individual's ASD and the family's quality of life or the uncertainty regarding the individual's ASD and the family's quality of life. The results and implications of this study will be further discussed in Chapter Five.

CHAPTER 5

Discussion

This current study explored factors that either detract from or contribute to the family's adaptation in families of individuals diagnosed with an ASD. Two theories, the FAAR model (Patterson, 1988, 1989, 2002, 2005) and the Family Systems-Illness Model (Rolland, 1984, 1987, 1994, 1999, 2003) were used to identify specific factors for examination and the underlying mechanisms by which family adaptation to chronic illnesses or disabilities, such as ASDs, is thought to occur. The factors investigated in this current study represent two demand factors that are thought to directly influence the family's adaptation and three family beliefs that are thought to both directly and indirectly influence family adaptation.

This chapter begins with a brief review and discussion of the findings of this study, presented by variable. Specifically, findings for the two family demand factors (i.e., uncertainty regarding an individual's ASD and the perceived severity of an individual's ASD) are presented, followed by the findings for the three family beliefs (i.e., optimism, control, and mastery). Next, implications of these findings are discussed with regards to theory, practice, and research. Finally, the limitations of this study are reviewed.

Demand Factors

Uncertainty

As predicted, participants' uncertainty regarding an individual's ASD was found to be significantly and negatively related to participants' satisfaction with their family's quality of life. Uncertainty, as measured by the PPUS, predicted nearly 23% of the variability in family quality of life (FQOL) scores. Relatively few studies have examined the relationship between caregiver's uncertainty regarding an individual's health condition and various outcomes in the chronic illness and/or disability literature. Nevertheless, the significant negative relationship between the PPUS and FQOL in this current study is consistent with this body of literature, namely that negative outcomes are related to heightened levels of uncertainty (e.g., Grootenhuis & Last, 1997; Jessop & Stein, 1985; Dodgson et al., 2000). For example, studies have demonstrated an association between caregivers' heightened levels of uncertainty regarding a child's health-related condition and several caregiver outcomes, including global distress, anxiety, and depression (e.g., Grootenhuis & Last, 1997; Jessop & Stein, 1985; Sanders-Dewey, Mullins, & Chaney, 2001). In addition, heightened levels of uncertainty have also been linked to family or social disruption (e.g., Dodgson et al., 2000; Garwick et al., 2002). The findings of this current study add to this literature and suggest that caregivers' uncertainty regarding their child's developmental disability also has implications for the family's quality of life.

Within the literature specific to ASDs, no quantitative studies were found to have focused on the impact of uncertainty regarding an individual's ASD on either individual

or family level outcomes. Several qualitative studies, however, have noted that uncertainty is often a common theme within the lives of families of children diagnosed with an ASD (e.g., Gray, 2002; O'Brien, 2007). For example, these narrative themes have highlighted caregivers' uncertainty regarding the future outcomes of their child diagnosed with an ASD (e.g., Gray, 2002; O'Brien, 2007), daily changes in the child's functioning (O'Brien, 2007), and appropriate expectations for the child's skill level (O'Brien, 2007).

The results of this current study provide a good quantitative complement to these documented themes. The measure of uncertainty utilized in this current study (i.e., the PPUS) reflects four areas of uncertainty that caretakers of individuals diagnosed with an illness or disability may experience, including uncertainty related to: 1) appropriate care for the child; 2) treatment and systems of care; 3) daily and future predictions of symptoms and outcomes; and 4) the relative seriousness of a condition (Mishel, 1983). Thus, the themes related to uncertainty that are present within the ASD qualitative literature are also reflected in the PPUS. While the results of this current study examined the influence of these four areas of uncertainty as a whole, rather than as separate subscales, these results suggest that general uncertainty regarding an individual's ASD is not just a caregiver concern, but is also directly associated with negative outcomes. While only the family outcome of family quality of life was examined in this current study, it may be warranted for future research to examine whether the link between uncertainty and individual outcomes, congruent with those reflected in the broader

chronic illness/disability literature, are applicable to experiences of families managing ASDs.

In summary, the relationship between participants' uncertainty regarding an individual's ASD and their satisfaction with their family's quality of life evidenced in this current study is consistent with the associations reported in the broader literature on caregivers of individuals diagnosed with a chronic illness or disability. In addition, it may be that the findings regarding the impact of uncertainty from the broader chronic illness/disability literature are applicable to the specific experience of families managing ASDs. If so, it appears that conceptualizing uncertainty as a variable with important implications could be warranted and suggests that further examination is needed on the role of uncertainty in the lives of families of individuals diagnosed with an ASD.

Severity

As predicted, participants' perception of the severity of their child's ASD was found to be significantly and negatively related to their satisfaction with their family's quality of life. Perceived severity, as measured by the PCQ, predicted nearly 18% of the variability in family quality of life (FQOL) scores. The significant negative relationship between the PCQ and FQOL in this current study is consistent with the majority of past ASD-specific research linking negative outcomes to higher levels of severity of a child's ASD. A large majority of this research has demonstrated relationships between greater indicators of ASD severity and negative caregiver outcomes, such as stress and symptoms of depression (e.g., Donovan, 1988; Dumas, Wolf, Fisman & Culligan, 1991; Hanson & Hanline, 1990; Konstantareas & Homatidis, 1989; Plant & Sanders, 2007). No

studies, however, were found to have examined the impact of the severity of an individual's ASD on family-level outcomes. Thus, the findings of this current study suggest that the perceived severity of a child's ASD can also negatively influence family-level outcomes such as family quality of life.

Of note in this current study is the way in which ASD severity was defined. Previous research regarding the impact of ASD severity on caregiver outcomes has utilized varying definitions of severity. For example, several studies that noted an association between negative outcomes and ASD severity defined ASD severity as greater deficits in diagnostic domains (e.g., Frey, Greenberg, & Fewell, 1989; Konstantareas & Homatidis, 1989) or as greater difficulties in related behavioral areas, including conduct issues, stereotypy, or self-injurious behaviors (e.g., Konstantareas & Homatidis, 1989; Dumas, Wolf, Fisman, & Culligan, 1991; Hastings, 2003). Across these studies, severity has typically been measured using autism-specific behavior checklists, general adaptive behavioral scales, or conduct-specific behavioral scales, all of which objectively measure the presence, frequency, and/or intensity of particular behaviors.

In this current study, the PCQ was specifically chosen as an indicator of ASD severity because it incorporates both diagnostic-specific criteria as well as related behavioral issues. Moreover, unlike a rating scale that objectively measures a behavior or concern, the PCQ is a subjective rating scale that measures the extent to which a caregiver views a particular behavior or issue as a problem. This distinction was theoretically important in this current study given Rolland's (e.g., 1994, 1999) definition

of incapacitation or severity. That is, Rolland (1994, 1999) suggests that the impact of an illness or disability's severity not only depends on the level and type of impairment, but also how well the family is able to manage the impairment. This implies that it could be important to ascertain not only the objective presence of behavioral issues and diagnostic-specific criteria, but also the extent to which a caregiver perceives these issues as present and severe. Since prior research has overwhelming utilized objective scales, the PCQ was thought to be a good compliment to this literature.

Overall, item analysis of the PCQ indicated several factors of note. First, participants as a group indicated relatively mild to moderate impairments across items. This may be more mild than expected, given that the sample reflected a somewhat balanced split among children's diagnoses (i.e., 33.3% Autism; 40.6% PDD-NOS; 26.1% Asperger's Syndrome). Second, as a group, participants endorsed social interaction deficits, attention span deficits, and anxiety as the most severe behavioral symptoms, with aggression and self-injurious behaviors as the least severe. As such, only one of the core diagnostic criteria (i.e., social interaction) was identified as being among the most severe issues. In addition, the related behavioral symptoms (i.e., aggressive or self-injurious behaviors) past research has identified as being important predicators of negative parental outcomes (e.g., Dumas et al, 1991, Konstantareas & Homatidis, 1989) were not rated as severe as other issues in this current study. While additional analyses of PCQ scores with respect to diagnosis is warranted, these overall group findings could also be a reflection of the sample (i.e., caregivers who chose to participate may perceive their children to be less severe) or of the subjective nature of the PCQ.

Even without highly endorsing the diagnostic-specific criteria or conduct issues that previous research has suggested as important indicators of severity, this current study provided support for the impact perceptions of severity can have on outcomes. This is consistent with the research on caregivers' perceptions of chronic illness. For example, Ireys and Silver (1996) reported that mothers who perceived their child's chronic illness to have a greater impact on the family were more likely to experience mental health issues, regardless of the actual medical severity of the child's condition. It could be that the extent to which a caregiver perceives their child's ASD to be severe is as important as the actual presence of deficits in functioning. If so, further research regarding the link between subjective and objective ASD severity and outcomes is needed.

In summary, this study found a moderate negative relationship between the perceived severity of a child's ASD and the family's quality of life. The relationship between the perceived severity of a child's ASD and the family's quality of life evidenced in this current study is consistent with the large majority of research on the impact of ASD severity. The indicator of ASD severity in this current study was subjective in nature, that is, it measured caregivers' perception of severity, rather than the objective measures utilized in previous research. Additionally, aspects of severity that have been found to be specifically linked to poorer caregiver outcomes, including diagnostic-specific factors, conduct issues, and/or self-injurious behaviors, were not as highly endorsed in this current study as other issues. Given that this current study provided evidence that perceived ASD severity is associated with the family's quality of life, it could be that, as Rolland (e.g., 1994, 1999) suggests, both subjective and objective

appraisals of the severity of an individual's ASD are important in determining the impact of an individual's ASD. If so, further research in this area may be warranted.

Family Beliefs

Optimism

As predicted, optimism was positively and significantly related to the participants' satisfaction with their family's quality of life. Optimism, as measured by the LOT-R, predicted 12.4% of the variability in family quality of life (FQOL) scores. In addition and also as predicted, optimism was found to be a statistically significant partial mediator of both the relationship between the perceived severity of an individual's ASD and the family's quality of life and the relationship between the uncertainty regarding an individual's ASD and the family's quality of life.

While these findings are consistent with previous research, relatively few studies have focused on the role of optimism in families' experience with ASDs or other developmental disabilities. What research exists has demonstrated that caregiver optimism, as defined as dispositional optimism, is linked with positive outcomes. For example, in a study examining group differences between families of children diagnosed with a developmental disability, families of children with borderline delays, and families of non-delayed children, optimism was found to have a positive association with parental well-being (Baker, Blacher, & Olsson, 2005). Similarly, in a study examining between group and within group differences with mothers of adults with Down Syndrome, mothers of adults diagnosed with schizophrenia, and mothers of adults diagnosed with

autism, optimism was found to be associated with positive well-being and a better parent-child relationship quality (Greenberg et al., 2004). This current study further expands the literature on the role of optimism with caregivers of individuals diagnosed with chronic health conditions by also providing evidence that dispositional optimism is positively associated with the family's quality of life.

Additionally, this current study provides further evidence to the complex role optimism plays in fostering positive outcomes. Findings from this current study suggest that, for some people, optimism may play an important mediator role between the uncertainty related to an individual's ASD or the perceived severity of an individual's ASD and the family's quality of life. Although relatively little research exists on this area, this study's findings are consistent with the previous literature. Specifically, past research has demonstrated that optimism can mediate the relationship between the mother's relationship quality with their adult child diagnosed with an ASD and the mother's well-being (Greenberg et al., 2000). Optimism has also been found to moderate the relationship between child behavior problems and parental well-being (Baker, Blacher, & Olsson, 2005). Collectively, it appears that dispositional optimism may influence the relative impact of some demands or stressors on caregiver and family outcomes. As such, these findings could be construed as support for the use of the FAAR model (e.g., Patterson, 1993, 2005) in conceptualizing the role of family beliefs or meanings, such as dispositional optimism, in promoting optimal adaptation to a family member's health condition. If so, the extent to which caregivers are optimistic about

their life could pose a potential intervention target for practitioners working with families of individuals diagnosed with an ASD.

It should be noted that this current study chose to examine dispositional optimism rather than optimism regarding future outcomes related to an individual's ASD. Rolland (e.g., 1994, 1999) notes that both the extent to which family members are optimistic towards their life in general, as well as their optimism towards the specific disability or illness they face, are thought to influence adaptation and response to the particular health condition. While this current study focused on dispositional optimism, situation-specific optimism, i.e., optimism towards future outcomes for the individual diagnosed with an ASD, could also play a significant role in family members' adaptation and response to an individual's ASD. Consequently, future research regarding the role of both dispositional optimism and optimism regarding an individual's ASD may prove beneficial.

In summary, the relationship between participants' dispositional optimism and their satisfaction with their family's quality of life evidenced in this current study is consistent with the associations reported in the broader literature on caregivers of individuals diagnosed with an ASD or other developmental delays. In addition, for some people optimism may mediate the relative impact of the uncertainty related to an individual's ASD or the perceived severity of the individual's ASD on the family's quality of life. As such, optimism could pose a potentially promising intervention target for family-focused practice in families of individuals diagnosed with an ASD.

Control

Although no research exists that focuses on the influence of health locus of control in families managing ASDs, there does exist a limited body of related research on the role of locus of control in caregivers of individuals diagnosed with an ASD, and more broadly, caregivers of individuals managing chronic health conditions. Collectively, this literature suggests that caregivers with a greater internal locus of control tend to score lower on negative outcome measures (e.g., depression indices) and higher on positive outcome measures (e.g., well-being indices) than caregivers with less internal locus of control (e.g., Brown, 1993; Dunn et al., 2001; Friedrich, Cohen, & Wilturner, 1988).

In accordance with these past findings, this current study hypothesized that internal health locus of control would positively predict the family's quality of life, a family-level outcome. Health locus of control was defined in this current study as the extent to which the individual, chance, or professional has personal control over the course or outcomes of an individual's ASDs. The findings of this current study did not support this hypothesis. The relationship between family quality of life and other dimensions of health locus of control, that is health locus of control related to chance and professionals, were subsequently explored. Chance health locus of control was not found to be predictive of family quality of life. While professional health locus of control was found to be a statistically significant positive predictor of family quality of life, the strength of this relationship was relatively weak, with professional health locus of control accounting for 4.3% of the variability in family quality of life scores.

Emerging areas of study in the health locus of control literature are the relationships between the various dimensions of this multidimensional construct. Several authors have suggested that additive or interactive relationships between different dimensions of health-related locus of control may provide a better fit with individuals' health-related experiences (e.g., Affleck & Tennen, 1993; Masters & Wallston, 2005: Taylor, Helgeson, Reed, & Skokan, 1991). Only one study specifically focusing on caregivers of individuals diagnosed with a chronic health condition was found to utilize this approach. This study, which focused on caregivers of children with cerebral palsy, noted that caregivers who scored high in both internal and chance health locus of control dimensions reported greater social support and less subjective burden (Green, 2004). In this vein, this current study examined the extent to which the combination of internal health locus of control and chance health locus of control would be predictive of family quality of life. Unlike the findings reported by Green (2004), this current study did not find the combination of internal health locus of control and chance health locus of control to be a statistically significant predictor of family quality of life. While the combination of internal health locus of control and professional health locus of control was found to be a statistically significant positive predictor of family quality of life, the strength of this relationship was relatively weak, accounting for 4.5% of the variability in family quality of life scores.

Finally, this study predicted that health locus of control would mediate both the relationship between the perceived severity of a child's ASD and the family's quality of life and the relationship between the uncertainty regarding a child's ASD and the

family's quality of life. These hypotheses were not supported. Specifically, all three subscales of health locus of control did not mediate either the relationship between the perceived severity of a child's ASD and family quality of life or the uncertainty regarding a child's ASD and the family's quality of life.

Given the findings of the broader chronic illness and disability literature, this current study's health locus of control findings with caregivers of individuals diagnosed with an ASD are surprising. There could be several potential explanations for these findings. First is the issue of how control was measured. The concepts of optimism and mastery were operationalized in this study by general, or global, instruments, while control was operationalized by a situation-specific instrument. The majority of past literature examining the role of locus of control in caregivers of individuals with chronic illnesses or disabilities (e.g., Bookwala & Schulz, 1998; Friedrich, Cohen, & Wilturner, 1988; Miller et al., 1995), including the limited literature on caregivers of individuals diagnosed with an ASD (e.g., Dunn et al., 2001), have utilized global locus of control constructs. While these studies all demonstrated support for the relationship of internal locus of control to positive outcomes, it could be that these global locus of control findings are not generalizable to the situation-specific construct of health locus of control. This would be surprising, though, given that studies that have utilized situation-specific locus of control measures, such as parenting locus of control (e.g., Hassall, Rose, & McDonald, 2005; Jones & Passey, 2005) and health locus of control (e.g., Green, 2004), have supported these more global trends.

Control-related findings of this current study could also be the result of the outcome measure. Specifically, the situation-specific health locus of control measure may demonstrate a different relationship with a family-focused, rather than individual-focused, outcome. Within the research on caregivers of chronically ill or disabled individuals that utilized locus of control in their studies, the outcome variables have been either individual outcomes, such as subjective burden, depression, and well-being (e.g., Bookwala & Schulz, 1998; Brown, 1993; Green, 2004; Miller et al., 1995), or relational outcomes, such as social support (Green, 2004). In the context of these past studies, it could be that the internal and chance health locus of control findings of this current study reflect a lack of a statistically significant relationship with more global family-level outcomes.

Additionally, the assumed relationships tested by this current study could be inappropriate. That is, internal and chance health locus of control may be influential, but in ways not tested by this current study. For example, it may be that internal and chance health locus of control act as moderators of the relationship between family demands and the family's quality of life. Or, internal and chance health locus of control may have relationships with other outcomes or beliefs beyond those tested in this current study. Finally, internal and chance health locus of control may be related to other variables in this study in meaningful ways, but not as predicted by the theories underlying this current study's hypotheses. Thus, further research regarding the potential role of internal and chance health locus of control is warranted.

Finally, the control-related results of this current study could be a reflection of a group-specific difference. That is, health locus of control could be related to outcomes in unexpected ways for caregivers of individuals diagnosed with ASDs as compared to other chronic illness or disability groups. This explanation finds some support in this study's findings that professional health locus of control has a significant, although relatively weak, relationship with the family's quality of life. Although there exists relatively less literature on professional or powerful others health locus of control (Mackenbach et al., 2001), some points from that literature may help to explain this current study's findings.

First, although people in general adjust to stressful events better when they perceive more control over the consequences (e.g., Shapiro, Schwartz, & Astin, 1996; Smith, Dobbins, & Wallston, 1991; Taylor, Helgeson, Reed, & Skokan, 1991; Taylor et al., 2000), a few exceptions exist. Most notably, in their prospective research on medically fragile infants, Affleck and Tennen reported that when mothers brought their infants home from the hospital and believed that their child's future health and development was largely dependent upon their personal actions, these mothers tended to display greater emotional distress (Affleck & Tennen, 1993). The authors further noted that some mothers made burdensome accommodations that had negative impacts to their own well-being or that of the family in order to retain the level of internal control they thought they needed to produce optimal change (Affleck & Tennen, 1993). Other mothers in this study noted that the greater attention they gave to achieving the most optimal outcomes for the child made them experience greater pressure regarding the selection of, and implementation of, the best treatments and also highlighted the presence

of minor problems or lack of response of the child to those treatments (Affleck & Tennen, 1991). Thus these studies highlight examples in which internal health locus of control did not relate to outcomes in the expected manner.

Affleck and Tennen further noted that families sometimes abandon a large amount of control to care providers in medical settings, particularly when under a very threatening situation and when they believe that desired outcomes can be better controlled by others, such as doctors or professionals (Affleck & Tennen, 1991). These authors suggested that caregivers' views of control in these situations may better reflect "participatory" and "vicarious" control (Affleck & Tennen, 1991, pp. 9). Participatory control emphasizes a partnership between the parent and the professional in which the parent recognizes the competence of the professional, both in regards to their knowledge and treatment skills, while the professional provides the information necessary to the parent to make informed decisions and actively solicits the parents' participation in decision making (Affleck & Tennen, 1991). Vicarious control involves relinquishing all decisions to an authoritative other, such as the professional (Affleck & Tennen, 1991). Utilizing these categories, the findings were suggestive: of their sample, 25% of mothers successfully sought out and engaged in participatory control, 50% of mothers were uninterested in gaining participatory control over their child's treatment and instead held vicarious control beliefs, while a final 20% of mothers unsuccessfully sought to engage in participatory control with their child's professionals (Affleck & Tennen, 1991). The desire, yet failure, to achieve participatory control reportedly had long term negative

effects, including a greater proportion of these mothers recounting painful memories of their child's hospitalization (Affleck & Tennen, 1991).

Afflect and Tennen's (1991, 1993) work could be useful in understanding the health locus of control findings of this current study. First, an argument could be made that families of individuals diagnosed with an ASD and the population of Affleck and Tennen's (1991) study share similar characteristics. For example, the mothers in Affleck and Tennen's (1991) study were providing care to children with severe and intense needs in multiple domains, were uncertain regarding day-to-day and long-term course of functioning for their children, and their children had unclear outcomes. These variations in domain deficits, course, and future outcomes are similar to those faced by families of individuals diagnosed with an ASD. In addition, the children in Affleck and Tennen's (1991) study had high levels of medical professional involvement. As with the families in Affleck and Tennen's study (1991), families of individuals diagnosed with ASDs oftentimes have high levels of professional involvement, either through school placements, behavioral services, outpatient services, or medical settings. Thus, it can be argued that on a conceptual level, Affleck and Tennen's (1991) findings may be applicable to families of individuals diagnosed with ASDs.

If so, then the lessons learned in Affleck and Tennen's (1991) study could inform this current study's findings. That is, the findings of this current study could suggest a great variability exists in the way parents of individuals diagnosed with ASDs view sources of control and that traditionally accepted models of internal and external health locus of control may not be appropriate with this population. Instead, further aspects

experienced by families of children diagnosed with ASDs could complicate the relationship of health locus of control with outcome measures. For example, treatments for ASDs can involve a large number of individual intervention hours across multiple (i.e., school, home, and community) settings, thus necessitating high level of direct involvement and professional contact. As such, it is not surprising that caregivers would endorse professionals as the main agents of change for their children diagnosed with ASDs. Variables including treatment intensity or satisfaction could be complicating factors that influence the relationship between internal health locus of control and outcomes. Thus, further examination of the roles of different dimensions of health locus of control beliefs in groups of caretakers' of individuals diagnosed with ASDs is warranted.

In summary, this current study found no relationship between participants' internal, chance, or combination of internal and chance health locus of control and their satisfaction with their family's quality of life. Professional health locus of control and the combination of internal and professional health locus of control were found to have weak, but statistically significant, relationships with family quality of life. No dimension of health locus of control (i.e., internal, chance, professional) was found to mediate the relationship between either uncertainty or perceived severity and family quality of life. These findings differ from findings within the majority of literature on caregivers of individuals with a chronic illness or disability and may be a reflection of either how control was measured, the outcome measure utilized in this current study, the relationships tested within this current study, or a group-specific difference in the role of

health locus of control. As such, further research may be useful in understanding the role of control beliefs in the lives of families of individuals diagnosed with an ASD.

Mastery

As predicted, mastery was positively and significantly related to participants' satisfaction with their family's quality of life. Mastery, as measured by the SOC-13, predicted nearly 21% of the variability in family quality of life (FQOL) scores. In addition and also as predicted, mastery was found to be a statistically significant partial mediator of both the relationship between the perceived severity of an individual's ASD and the family's quality of life and the relationship between the uncertainty regarding an individual's ASD and the family's quality of life.

These findings are consistent with the literature on the influence of mastery beliefs in the lives of families of individuals with general chronic illnesses or disabilities, as well as the limited literature on families of individuals specifically diagnosed with an ASD. Previous studies have demonstrated that mastery, as defined by sense of coherence, is negatively related to caregiver outcomes, such as depression (Olsson & Hwang, 2002) and stress (Margalit & Kleitman, 2006). Evidence from the literature also suggests that a negative relationship exists between sense of coherence and family strain (Sivberg, 2002). This current study's findings further expands the literature on the role of mastery beliefs in families of individuals diagnosed with an ASD by demonstrating a link between mastery beliefs and the family's quality of life. Thus, this study's findings that mastery beliefs, specifically sense of coherence, can directly influence family-level variables like family quality of life is consistent with the findings in the broader literature

on families of chronically ill or disabled individuals (e.g., Svavarsdottir, Rayens, & McCubbin, 2005), providing further support that mastery is an important aspect within the lives of families managing chronic illnesses or disabilities, including ASDs.

The findings of this current study also suggest that mastery beliefs may play a complex role in the lives of caregivers of individuals diagnosed with an ASD. As this current study suggests, for some people mastery beliefs can mediate the relationship between specific demands placed upon the family (i.e., uncertainty related to a child's ASD, perceived severity of the child's ASD and related symptoms) and the family's quality of life. This finding is consistent with the limited previous research on caretakers of individuals diagnosed with a chronic illness or disability. Specifically, Svavarsdottir and colleagues (Svavarsdottir, Rayens, & McCubbin, 2005) provided evidence that sense of coherence moderates the relationship between demands placed upon a family and family adaptation. Taken together, these findings suggest that mastery beliefs may play a complex positive role in the lives of families managing chronic illness/disabilities, including ASDs. As such, helping caregivers enhance their feelings of mastery could pose an important potential intervention target for practitioners working with families of individuals diagnosed with an ASD.

In order to enhance these feelings of mastery, it may be important to specifically examine the aspects of sense of coherence individually and collectively. Sense of coherence is defined as the extent to which an individual finds their environment to be comprehensible or orderable, their demands to be manageable, and their life to be meaningful (Antonovsky, 1987). Together, these aspects are thought to reflect general

mastery beliefs, and as such, were examined collectively in this current study. One could argue, however, that these three components should be examined separately, since they each could manifest themselves differently in practice. Further research examining these aspects of sense of coherence individually, therefore, may be useful.

In summary, the relationship between participants' mastery beliefs and their satisfaction with their family's quality of life evidenced in this current study is consistent with the associations reported in the broader literature on caregivers of individuals with chronic illnesses or disabilities, including ASDs or other developmental delays. In addition, for some people general mastery beliefs may mediate the relative impact of the uncertainty related to a child's ASD or the perceived severity of the child's ASD on the family's quality of life. As such, mastery beliefs could pose a potentially promising intervention target for family-focused practice in families of individuals diagnosed with an ASD.

Implications for Theory and Practice

Results from this study have several general implications for theory and practice. First, this study utilized developmentally-informed theories, such as developmental systems (e.g., Bronfenbrenner, 1986; Ford & Lerner, 1992; Lerner, 1991) and developmental psychopathology (e.g., Cicchetti & Rogosch, 1996; Cicchetti & Sroufe, 2000), as overarching organizational frameworks within which to ground this study's hypotheses and variable selection. Together, these theories highlight the importance of examining the dynamic relationship between the individual and various systems, or

contexts, within which the individual is embedded. In addition, these theories also suggest that the accumulation of multiple risk and protective factors, and the interplay between risk and protective factors, lead to optimal and less than optimal outcomes.

The results of this current study identified and provided initial support for specific risk (e.g. perceived severity and uncertainty) and protective factors (e.g., optimism and mastery), as well as potential processes, that appear to be influential in how a family adapts to a family member's ASD. Additionally, results from this current study highlight what could be construed as the complex relationship between aspects of an individual's ASD and the family context. Given the complexities inherent within these developmentally-informed theories, particularly their dynamic, contextual, and temporal nature, additional research is needed to identify further risk and protective factors and the processes by which resilience is fostered in families of individuals diagnosed with an ASD. Developmentally-informed research that examines the interplay between contexts, as well as the interactional or transactional nature of risk and protective factors, may prove useful in further informing our understanding of families' experience with ASDs.

In addition, this study tested the applicability of two specific theories that have been used in the broader chronic illness and disability literature but have been relatively untested within the ASD literature. These theories, namely the FAAR model (e.g., Patterson, 1989, 2005) and the Family Systems-Illness Model (e.g., Rolland, 1994, 1999, 2003), identify factors that theoretically influence the adaptation and well-being of families faced with chronic illness or disability, as well as detail the theoretical relationship among these factors. The findings of this study could be viewed as initial

support for the use of both the FAAR model (e.g., Patterson, 1989, 2005) and the Family Systems-Illness Model (e.g., Rolland, 1994, 1999, 2003) in conceptualizing the experience of families of individuals diagnosed with ASDs.

The FAAR model (e.g., Patterson, 1989, 2005) was particularly useful in this current study for conceptualizing factors within broad categories (i.e., demands/risk factors, capabilities/resilience factors, beliefs, adaptation) and hypothesizing potential relationships among these categories. The results of this current study could be construed as support for the relationships between capabilities/demands, beliefs, and adaption posited by the FAAR model (e.g., Patterson, 1989, 2005). Specifically, this current study classified the factors under examination as demands (i.e., perceived severity of an individual's ASD and the uncertainty related to an individual's ASD), beliefs (i.e., optimism, control, mastery), or adaptation (i.e., family quality of life), and then tested the relationships hypothesized by the FAAR model among these factors. Results from this current study demonstrated that identified demands were related to family adaptation in the manner suggested by the FAAR model. Additionally, two of the identified beliefs in this current study (i.e., optimism and mastery) were found to be related to both demands and adaptation as suggested by the FAAR model. As such, the FAAR model could be a good conceptual guide for directing interventions when the outcome of focus is the family system.

In addition to the relationships posited by the FAAR model (e.g., Patterson, 1989, 2005), the Family Systems-Illness Model (e.g., Rolland, 1994, 1999, 2003) could also have important implications for interventions with families of individuals diagnosed with

ASDs. This study selected factors identified by Rolland (e.g., 1994, 2003) as particularly salient aspects of the chronic illness or disability experience, including disability-specific characteristics (e.g., perceived severity, uncertainty) and specific types of beliefs held by family members (e.g., optimism, control, mastery). The results of this current study provide some support that these disability-related characteristics and certain beliefs (i.e., optimism, mastery, and professional health locus of control) are also salient aspects of the family's experience with ASDs. While further research is needed, the Family Systems-Illness Model (e.g., Rolland, 1994, 1999, 2003) could prove a useful general framework for clinical interventions with families of individuals diagnosed with ASDs.

Current intervention and treatment practice with families of individuals diagnosed with an ASD typically assume one of eight general approaches (Marcus, Kunce, & Schopler, 2005). The majority of these approaches tend to focus on promoting positive individual and family outcomes through increasing concrete skills, knowledge, and/or resources (Marcus, Kunce, & Schopler, 2005). These approaches could be construed as important interventions that target the demands and capabilities of families of individuals diagnosed with ASDs. In addition, and as noted by Marcus and his colleagues (Marcus, Kunce, & Schopler, 2005), some families may benefit from interventions that target the cognitive and emotional elements inherent with having a family member diagnosed with an ASD. This type of supportive counseling approach has received relatively little focus in the ASD literature. The findings of this current study, embedded within the related literature on ASD and other chronic illnesses and/or disabilities, suggest that counseling approaches that are thought to be beneficial for families of individuals with chronic

illnesses or disabilities (e.g., Family Systems-Illness model, Rolland, 1994, 1999; Medical Crisis Counseling, Koocher & Pollin, 1994), and which often explore these demands and family beliefs, could also be useful models with families of individuals diagnosed with an ASD. Further research regarding the applicability of these theories to families of individuals diagnosed with ASDs, therefore, could prove useful to family-focused interventions.

An underlying goal of this current study was to examine specific factors that may prove useful as targets for intervention practice. As the numbers of individuals diagnosed with ASDs grow, professionals will increasingly be asked to provide effective interventions that explicitly include the family context. While there exists a few good family-focused guides for practitioners (e.g., Marcus, Kunce, & Schopler, 2005; O'Brien & Daggett, 2006) and a growing literature on skill-building interventions for caregivers (e.g., Crockett, Fleming, Doepke, & Stevens, 2007; Harris, 1983; Tonge et al., 2006), there is a need for further quantitative research to help guide professionals, particularly those in the mental health field, with specific intervention targets for families of individuals diagnosed with an ASD. To this end, the findings of this current study, and the theories underlying its design, will hopefully be useful for understanding the complex nature of the family's adaptation to their ASD experience as well as highlight specific areas that could be useful in promoting positive adaptation in families of individuals diagnosed with and ASD.

One such area is the perceived severity of the child's ASD. This current study chose to use a broad, subjective conceptualization of ASD severity. Specifically, the

severity of an individual's ASD was defined to include the perceived problems with both diagnostic criteria and behavioral and emotional symptoms that are commonly associated with these disorders (McGrew et al., 2007). This broadened definition of severity was used because it more closely resembled the definition of illness/disability severity used in the Family Systems-Illness Model (Rolland, 1994, 1999, 2003) and also reflects the broader range of issues that families of individuals diagnosed with ASD manage. The support found in this study for the impact perceived severity has upon the family system suggests that practitioners working with families of individuals diagnosed with ASDs need to bear in mind the multiple ways severity can be defined.

First, it may be important to assess both the perceived level of severity of an individual's ASD as well as the objective presence and intensity of deficits. As Rolland notes, severity of an illness or disability is dependent upon the presence of both objective and subjective impairments (Rolland, 1994, 1999). Some families may perceive their family member's ASD severity differently than that of the professionals working with the family. As this current study suggests, and research in the chronic illness literature (e.g., Ireys & Silver, 1996) supports, caregivers' perceptions of ASD severity may have important implications on individual and family outcomes. Thus, by assessing both the objective and subjective levels of ASD severity, professionals could be better equipped to address family's treatment questions, particularly regarding potential discrepancies between objective and subjective severity of deficits.

Second, it could also be important for practitioners to assess the pattern of deficit severity. In ASDs, multiple areas of deficits often manifest in a variety of ways (National

Research Council, 2001; Volkmar & Klin, 2005). As Rolland (1994, 1999) posits, and as some research supports (e.g., Wang et al., 2004), families could view the severity of their family member's ASD not in terms of the objective severity of deficits in diagnostic-specific areas, or the presence of deficits in auxiliary areas of functioning, but as the relative 'fit' of the child's skill deficits with the resources available to the family. As Patterson (e.g., 1989, 2005) and other stress-focused models (e.g., McCubbin & Patterson, 1989) posit, the pile up of behavioral demands upon the family may be as stressful as the presence of one or two severe deficits. Thus, family-focused practitioners working with families of individuals diagnosed with ASDs may benefit from being cognizant of the way in which the family defines severity, as well as the areas that are most salient to the family's level of stress, when developing appropriate interventions.

Another potential target for intervention is the uncertainty caregivers have related to the individual's ASD. In this study, uncertainty was defined globally to encompass several aspects of ASD-related experience, including ambiguity related to caring and planning for their children, knowledge and understanding of the child's diagnosis, the diagnosis' course, available treatments and the various systems of care with which they are associated, as well as the relative unpredictability of outcomes (Mishel, 1982). As the results of this current study support, uncertainty appears to be an important aspect in the lives of families of individuals diagnosed with an ASD that is negatively related to the family's quality of life. Thus, it appears that Rolland's (e.g., 1994, 1999, 2003) suggestion that uncertainty is an overarching variable with considerable influence on the

illness/disability experience could be generalizable to families of children diagnosed with ASDs.

As such, uncertainty poses a potentially important area for targeted intervention. Given the definition of uncertainty used within this current study, several specific areas for targeted intervention could be useful. For example, psychoeducational approaches that provide information regarding the ASD diagnosis, the most recent research on treatment types and efficacy, and the systems involved in the care and treatment of the individual diagnosed with an ASD could be particularly important in reducing the relative impact associated with uncertainty regarding these areas. This functional approach to intervention is congruent with Marcus, Kunce, and Schopler's (2005) suggested treatment approaches with this population. Thus, it may be beneficial for future research to focus on whether or not interventions specifically designed to reduce family member's uncertainty have these anticipated effects upon individual and family outcomes.

Fostering general optimism in families of individuals diagnosed with an ASD may also be a useful target for intervention. This current study chose to examine the relative influence of general, or dispositional, optimism rather than optimism regarding the course and outcome of a family member's ASD. As suggested by the family resilience literature (e.g., Walsh, 2002, 2003) and the Family Systems-Illness model (e.g., Rolland, 1994, 1999), dispositional, or general, optimism is considered to be an important factor in facilitating optimal family functioning in the face of both general adversity and specific adversity related to a family member's health status. Dispositional optimism is believed to be important since individuals with expectations for positive outcomes tend to

persevere despite adversity because they accept the reality of a challenge, believe positive outcomes are obtainable, and engage in more active coping (e.g., Carver & Scheier, 2003; Rolland, 1994; Scheier & Carver, 2001; Scheier et al., 1989).

Additionally, it has been suggested that dispositional optimism may influence situation-specific beliefs and coping (Carver & Scheier, 2003; Scheier & Carver, 2001). If so, it could be that dispositional optimism influences one's optimism regarding a specific illness or disability, including ASDs, and/or the coping skills that are used to manage the condition itself. Although beyond the scope of this current study, it could be that dispositional optimism influences how families make meaning of various ASD-specific experiences or beliefs, such as optimistic views of the future outcomes for the individual diagnosed with an ASD. If so, further research examining both global and ASD-specific optimism may prove beneficial for practitioners.

Mastery beliefs may also be an important target for intervention. In this study, global mastery beliefs were defined by the variable sense of coherence, which encompasses the extent to which individuals view their lives as comprehensible, manageable, and meaningful (Antonovsky, 1987). The results of this study, in conjunction with previous support for the influence sense of coherence can have upon individual and family functioning in families of children diagnosed with ASDs (e.g., Olsson & Hwang, 2002; Sivberg, 2002), highlights the importance of mastery beliefs of families of children diagnosed with ASD. In intervention practice, however, these three components of sense of coherence could be targeted in different ways.

For instance, to promote beliefs regarding the comprehensibility of a caregiver's experience with their child's ASD, interventions could introduce ways in which a caregiver might make their environment more structured, predictable, and explicit. Interventions could involve having the caregiver focus on small, but significant, positive outcomes and building on these every day accomplishments. Additionally, interventions that introduced structure and predictability to the environment, such as family rules, role expectations, and schedules, could potentially be useful in enhancing mastery beliefs. Experiences that help families favorably compare their situation to others (e.g., 'downward comparisons,' Wills, 1981), even if only in one domain area, could foster feelings of manageability. Finally, interventions that help families construct positive meanings or find positive outcomes associated with having a family member diagnosed with an ASD could help lessen the negative impact of their situation. This last point in particular may be fruitful for further examination, in that relatively recent literature on families of individuals with a variety of disabilities, including ASDs, have noted a link between families identifying positive outcomes associated with having a family member with a disability and a variety of individual outcome measures (e.g., Krausss & Seltzer, 2000; Patterson, Garwick, Bennett, & Blum, 1997; Scorgie & Sobsey, 2000). Therefore, further research regarding these specific components of sense of coherence and their relative influence on individual and family adaptational outcomes in families of individuals diagnosed with an ASD could be useful.

Finally, the results of this current study regarding health locus of control differed from what was anticipated. While further research regarding the general role of health

locus of control, as well as different subsets including participatory or vicarious control, in family's adaptation to their family member's ASD is warranted, the results of this current study regarding professional health locus of control could have implications for practice. First, as suggested by the Family Systems-Illness model (e.g., Rolland, 1994, 1999), and the research on health locus of control (e.g., Andrykowski & Brady, 1994; Wallston, Wallston, Smith, & Dobbins, 1989), people who endorse this type of health locus of control orientation tend to be comfortable with intense professional involvement, but may have difficulty if the professional becomes unavailable, if treatment demands self-direction, or if the health-related condition is incurable. The vast majority of publicly-funded services for individuals diagnosed with an ASD currently end on or around the age of 21. Without a change in policy, it could be important for professionals to specifically, and concretely, help families plan for the eventual absence of professional involvement in their lives. This planning could involve many intervention practices, including ensuring that caregivers are instructed in delivering behavioral interventions and providing ways for caregivers to gain periodic consultation services leading up to and after formal services with their child is terminated.

In addition, for those families with high levels of professional health locus of control and who view the professional working with their family member diagnosed with an ASD as being the most important agent of change for that individual, that professional arguably gains considerable power within the clinical relationship. Given that collaborative work with the family is considered best practice in treatments of individuals diagnosed with an ASD (e.g., Marcus, Kunce, & Schopler, 2005; National Research

Council, 2001), the view of the professional as the most important agent of change suggests that professionals need to be highly aware of the power and influence they could have on these families. Thus, further research regarding family-professional relationships could prove beneficial in addressing elements that help promote positive collaborative work.

Implications for Future Research

This current study attempted to expand the research on families of individuals diagnosed with an ASD by examining the relative influence of specific variables on the family's quality of life, as well as the relationships among these variables. Over the course of this study, several areas for future study have emerged. First, as illustrated by the literature review on the variables included in this study, there exists a general need for further research on families of individuals diagnosed with ASDs. Oftentimes during this study's literature review, information from the broader chronic illness and/or disability literature was used to supplement the relatively sparse findings reported in the specific ASD literature. In doing so, this current study made assumptions that families managing ASDs would have similar reactions to their experiences as is generally reported on in the broader chronic illness and disability literature. The results of this current study demonstrated that families of individuals diagnosed with ASDs do have many similarities with the broader group of families of individuals diagnosed with chronic illnesses and/or disabilities, but also that some group differences may exist (e.g., health locus of control

beliefs). As such, further research regarding the extent to which these two populations are both similar to, and different from, each other would be beneficial.

This current study demonstrated that specific demand factors (i.e., perceived severity and uncertainty) are linked to the family's quality of life. Other demand or capability factors, also termed risk or protective factors, which have been identified in the individual and family resilience literature (e.g., Masten & Coatsworth, 1998; Walsh, 1998, 2003), were not the subject of focus in this current study. From the data collected in this current study, it may be useful to further examine how other factors within the resilience literature, such as socioeconomic advantages and the amount of and satisfaction with school or services (e.g., Masten & Coatsworth, 1998), also promote resilience in families of individuals diagnosed with an ASD. Additionally, future research could examine the role other previously identified risk and/or protective factors have in fostering optimal individual and family adaptation to a family member's ASD. These factors could include the individual diagnosed with an ASD's disposition and intellectual functioning, parenting style, marital and other family relationship factors, spiritualism or faith, and state-related policy regarding service types and availability (Mastern & Coatsworth, 1998; Walsh, 1998, 2003).

Future research may also wish to examine the relationship between other family beliefs, particularly those specific to their ASD experience, and individual and/or family outcomes. One such belief that could be important in promoting optimal adaptation to an individual's ASD is caregivers' beliefs regarding the etiology of ASDs. Etiological beliefs are the narratives people form to organize and explain why a particular disability

or illness occurred (Rolland, 1994; 1999). These beliefs are considered to be important to assess given the potential for family members to assign blame to others for the occurrence of a disability or illness, as well as the potential for family members to feel guilty or blame themselves (Rolland, 1994; 1999). In addition, some authors have suggested that family's etiological beliefs regarding the development of an ASD may also be related to the family's routine health care choices (i.e., immunization), treatment choices (i.e., use of complimentary and alternative medicine), and confidence in their family physician (Harrington, Patrick, Edwards, & Brand, 2006). Thus, further research could examine the relative influence family's etiological beliefs have in individual and family outcomes, as well as treatment choice and use.

An aspect for further evaluation involves the use of subjective or objective measures when exploring the experiences of families of individuals diagnosed with ASDs. This current study used questionnaires (e.g., PCQ, FQOL) to measure participants' perceptions of their child's ASD severity and their family's quality of life. While the subjective nature of these instruments were a good fit for this current study, objective measures of severity or quality of life may relate with variables in different ways. As Rolland's (1984, 1994, 1999) concept of 'goodness of fit' between the psychosocial demands of a particular illness or disorder and the strengths of a particular family suggests, differences can exist between a family member's perceptions of their chronic illness or disability related experience and actual, or objective, measures of this experience. Thus, future studies may wish to further explore how subjective and

objective measures of the same construct (e.g., ASD severity, quality of life) may relate to each other and to the family's experience with ASD.

While not a focus of this current study, future research on families of individuals diagnosed with an ASD may also wish to explore group differences within this population. This current study reported general findings on the relationship between specific demand factors, beliefs, and the family's adaptation. Absent from this current study's analyses were the extent to which within group differences, including the child's specific diagnosis, may influence the results of this study. It could be that the relationships, and the strength of the relationships, found in this current study appear different for different diagnostic groups. Thus, further analysis is warranted. In addition, future research may wish to specifically focus on other demographic variables, such as race or ethnicity, caregiver gender, or community characteristics, which this current study was unable to examine given the participant demographics.

Also not a focus of this current study was the relative influence of types of treatments and service hours on individual or family outcomes. Participants in this current study noted a wide range of service hours in which their child diagnosed with an ASD participates. These service hours ranged from educational services, behavioral services commonly utilized at home or in the community, private therapies, and adult-related services for adults diagnosed with an ASD. Additionally, participants also noted the extent to which their child diagnosed with an ASD participated in complimentary or alternative treatments, including identifying which types of dietary restrictions, supplements, prescribed medication, or other alternative treatments they utilized. Future

research with this data, or additional studies, may choose to examine the role of service type and use in individual and family outcomes.

Future studies may also wish to examine the effect of the parent-professional relationship on individual and family outcomes. Collaborative work with families have become a standard for comprehensive practice (e.g., Marcus, Kunce, & Schopler, 2005; National Research Council, 2001). However, for some families and for some professionals, 'collaborative work' could have different definitions and may manifest itself in a variety of ways. As Affleck and Tennen's (1991) work suggests, families with children requiring a high level of professional involvement display different patterns of health related control beliefs and types of caregiver-professional relationships than other chronic illness or disability groups. Given the treatment frequency and intensity oftentimes involved in treatment for individuals diagnosed with ASDs, it may prove beneficial for further research that is focused on the role of the professional-parent relationship in fostering positive outcomes and that examines the elements of effective 'collaborative practice.'

Finally, future research should examine the factors that promote resilience and optimal adaptation at different points in the family's life cycle. As Rolland (1994) suggests, this lifespan approach to families faced with chronic illness or disability, including ASDs, necessitates examining the life cycle or phases of the specific disability, the individual diagnosed with a disability, and the family. These phases may include times of crisis or chronic functioning, or developmental phases or periods through which all individuals and families progress (Rolland, 1994). Some authors have suggested

examining the extent to which the age-related phase of the child (e.g., early childhood, middle childhood, adolescent, adult) is related to various outcomes (e.g., Gray, 2002; Marcus, Kunce, & Schopler, 2005), while others have suggested looking at significant transition periods, or periods of crisis such as the diagnostic process, for variations in individual and family outcomes (Rolland, 1994). While this current study did not examine outcomes with respect to the age of the child or time from first diagnosis, future examination of these variables could result in useful information that has applications for intervention and treatment planning.

Limitations

As with most studies, it is important to consider the limitations of this study when interpreting the study's results. First, as a cross-sectional study, causality and inferences regarding the direction of relationships are tentative at best. This is particularly important to note given the use of mediation analyses in this study. While theory and previous research informed the assumed relationships and direction of these relationships, other equivalent models could be used to explain the relationships between the predictor, mediator, and the criterion variables. Results from the mediation analyses should be used more as descriptive information that would benefit from further studies that include longitudinal research and multimethod designs.

Second, sample characteristics pose issues regarding the generalizability of this study's results. For example, the vast majority of participants identified themselves as white, non-Hispanic. While the racial composition of this sample reflects that which is commonly seen in the autism literature, it does not reflect the purported cross-cultural

prevalence of autism and highlights the need for further research that is culturally and ethnically diverse (Dyches et al., 2004). If how the family makes meaning of their experience is an influential aspect in promoting overall family adaptation to disabilities like ASDs, then it is important to understand how cultural differences express themselves in this process of meaning-making. Issues regarding general attitudes towards disability and associated stigma, beliefs regarding etiological origins of autism, family organizational structure including child and caregiver roles, the role of spirituality, and use and structure of support networks are just some examples of areas in which cultural differences may express themselves (Dyches et al., 2004). Thus, the results of this study should be used as initial information regarding the importance of family beliefs in family adaptation to ASDs that should also be examined within other cultural groups for areas of similarity and difference.

In addition, the gender composition of this sample was over representative of female caregivers. While the gender composition of this sample is also representative of the large majority of research on families of children diagnosed with ASDs, it does pose generalizability issues regarding the applicability of this study's findings to male caregivers. Past studies have noted mixed results regarding the comparable level of stress experienced by mothers and fathers of children diagnosed with an ASD (e.g., Sharpley & Bitsika, 1997; Hastings et al., 2005b). In addition, studies have suggested that different aspects of disabilities impose differing levels of stress to mothers and father of children with disabilities (e.g., Hastings, 2003; Hastings et al., 2005a). Given that male caregivers may focus attention on different aspects of their child's ASD, as well as

may evidence different ways of conceptualizing and coping with their experience, further research regarding the applicability of this study's findings to male caregivers is warranted.

This study's sample also consisted of participants that evidenced a moderate to high level of educational and financial resources, as well as a range of neighborhood contexts (i.e., primarily suburban and rural). These demographic characteristics may shape how participants view their family's overall experience, their general levels of optimism and mastery beliefs, and their ASD-specific control beliefs. For instance, families located in areas where access to services is more readily available, as well as families who are able to afford auxiliary treatments, may have differing views than those whose access to or experiences with treatments are more limited. In addition, similar to the previous discussion on potential cultural differences, socioeconomic differences in a variety of areas (e.g., attitudes toward disability and stigma, family organizational patterns, support networks, and future oriented beliefs, etc.) may also influence beliefs families hold regarding their family member diagnosed with an ASD as well as their disability-related experience.

This study's sample consisted of individuals who self-selected to participate. As such, they represent not the full gamut of families of individuals diagnosed with ASDs, but a subset. For example, families faced with severe ASD and associated behavioral issues, or conversely, those with children mainstreamed in typical educational settings and displaying very mild forms of ASDs, may not be well represented in this current study. In addition, those who chose to participate may be at a cognitive or emotional

place where they are better able to discuss the impact and implications of ASDs on their families without undue distress. Individuals still grappling with the implications of their child's diagnosis may not have participated in this study due to the material being too emotionally upsetting. Thus, this self-selection must be taken into consideration when generalizing the results to the large population of families of individuals diagnosed with an ASD.

In addition to sample bias issues, issues of measure bias may also exist. First, this study used both web-based and paper-based surveys to collect data. Online research has been demonstrated to produce results consistent with traditional research (e.g., Gosling, Vazire, Srivastava, & John, 2004). Nevertheless, while care was taken to ensure consistency between the web-based and paper surveys, that is, that they reflected the same content and as close as possible the same visual presentation, this study's results should be further examined for potential difference arising from the method by which data was collected.

A final issue with measure bias in this study involves the use of self-report measures. While self-report measures allow for participants' perceptions and beliefs to be quantified and applied to theory-specific constructs, it does limit the range of beliefs that participants can express to predetermined categories. Future research may enhance this current study's findings by using qualitative methods to capture potential nuances quantitative methods fail to detect. In addition, self-report measures such as the Parental Concerns Questionnaire (PCQ) and the Family Quality of Life Survey (FQOL) assess participants' perceptions of severity and family quality of life, and as such, are subjective

in nature. Arguments for the use of both subjective and objective information in measuring concepts like quality of life (e.g., Cummins, 2005) have been made, noting the importance of both the perceptions of the individual, as well as the individual's objective experience. Additional research may wish to assess these variables through solely objective means, as well as examine the similarities and differences produced by objective and subjective measures.

Conclusion

Over the past ten years, significantly greater numbers of children have been diagnosed with an autism spectrum disorder (ASD) than previously reported (Centers for Disease Control and Prevention, 2007). The diagnosis of an ASD carries with it a profound life-long impact in multiple areas of functioning (i.e., social, communication, behavioral or interest patterns). Consistent with developmentally-informed theories, such as developmental systems (e.g., Bronfenbrenner, 1986; Ford & Lerner, 1992; Lerner, 1991) and developmental psychopathology frameworks (e.g., Cicchetti & Rogosch, 1996; Cicchetti & Sroufe, 2000), these children are influenced by, and pose potentially severe implications for, a number of different ecological systems or contexts. One such ecological system is the family. The family system is recognized as a key component to comprehensive and collaborative intervention with children diagnosed with ASDs (e.g., Marcus, Kunce, & Schopler, 2005), as well as the main long-term interventionists in these children's lives (e.g., Bristol, 1985). Given the complexities and potential long-

term implications inherent with ASDs, it necessitates a better understanding of those factors that either promote or deter both individual and family functioning.

To this end, this current study utilized two specific theories, the FAAR model (Patterson, 1989, 2005) and the Family Systems-Illness Model (Rolland, 1994, 1999, 2003) to identify specific variables deemed influential in the lives of families managing chronic illness or disability, as well as the mechanisms by which family adaptation to chronic illness or disability is thought to occur, and examined the relative fit of these theories to the specific experience of families managing ASDs. Overall, this study lent support for the use of these two models in conceptualizing the experience of families of individuals diagnosed with ASDs as well as for guiding intervention, policy, and research with this population.

In addition, this study provided initial evidence to the importance of two specific demand or risk factors in the adaptation of families of children diagnosed with ASDs. Specifically, this study demonstrated a negative relationship between the perceived severity of an individual's ASD and the family's quality of life, as well as a negative relationship between the uncertainty caregivers have regarding their child's ASD and the family's quality of life. These results suggest the need for practitioners to be mindful of the impact these demands could have upon the family system and the need to potentially target these areas with appropriate interventions to alleviate, or at least attempt to address, their relative influence.

This study also emphasized the importance and complex role that two specific family beliefs have on families of individuals diagnosed with ASDs. That is, optimism

(i.e., dispositional optimism) and mastery beliefs (i.e., sense of coherence) can both directly influence the family's overall quality of life as well as indirectly influence the relationship between demands placed upon the family and the family's quality of life. Given the importance of these two factors, further research is needed to elucidate the relationship between the presence of these factors on individual child and caregiver outcomes. In addition, the findings of this study suggest that interventions designed to target these beliefs could have an important positive impact upon the family's quality of life and adaptation to their family member's ASD.

Finally, the results of this study also suggest that control beliefs may act in complex and different capacities than one might expect given the literature on the role of control beliefs in adaptation to chronic illness and disease. This study demonstrated support for the impact beliefs regarding the professional's level of control over the course and outcome of an individual's ASD can have on the family's quality of life, but otherwise did not find support for internal or chance health locus of control as influential factors. Given the large amount of literature on the importance of various control beliefs in managing chronic illness and disease, further research regarding the importance of control beliefs and the mechanisms by which they influence outcomes in families of individuals diagnosed with ASDs is warranted.

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Appendix A

Family Quality of Life

DIRECTIONS: This questionnaire is about how you feel about your life together as a family. Your "family" may include many people - mother, father, partners, children, aunts, uncles, grandparents, etc. For this questionnaire, please consider your family as those people who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and who support and care for each other **on a regular basis.**

For this questionnaire, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items below are things that hundreds of families have said are important for a good family quality of life. We want to know how **Satisfied** you are with these things in your family. Please check the boxes on the following pages that reflect your level of satisfaction with each item. Checking the **first** square means you are **very dissatisfied**. Checking the **fifth** square means you are **very satisfied**.

	How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither Dissatisfied nor Satisfied*	*Satisfied*	*Very Satisfied*
1.	My family enjoys spending time together.	☐	☐	☐	☐	☐
2.	My family members help the children learn to be independent.	☐	☐	☐	☐	☐
3.	My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
4.	My family members have friends or others who provide support.	☐	☐	☐	☐	☐
5.	My family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐

	How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither Dissatisfied nor Satisfied*	*Satisfied*	*Very Satisfied*
6.	My family members have transportation to get to the places they need to be.	☐	☐	☐	☐	☐
7.	My family members talk openly with each other.	☐	☐	☐	☐	☐
8.	My family members teach the children how to get along with others.	☐	☐	☐	☐	☐
9.	My family members have some time to pursue their own interests.	☐	☐	☐	☐	☐

	How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither Dissatisfied nor Satisfied*	*Satisfied*	*Very Satisfied*
10.	My family solves problems together.	☐	☐	☐	☐	☐
11.	My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
12.	My family members show that they love and care for each other.	☐	☐	☐	☐	☐
13.	My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐
14.	Adults in my family teach the children to make good decisions.	☐	☐	☐	☐	☐

	How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither Dissatisfied nor Satisfied*	*Satisfied*	*Very Satisfied*
15.	My family gets medical care when needed.	☐	☐	☐	☐	☐
16.	My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
17.	Adults in my family know other people in the children's lives (friends, teachers, etc.).	☐	☐	☐	☐	☐
18.	My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
19.	Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐

	How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither Dissatisfied nor Satisfied*	*Satisfied*	*Very Satisfied*
20.	My family gets dental care when needed.	☐	☐	☐	☐	☐
21.	My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐
22.	My family member with an autism spectrum disorder has support to accomplish goals at school or workplace.	☐	☐	☐	☐	☐

	How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither Dissatisfied nor Satisfied*	*Satisfied*	*Very Satisfied*
23.	My family member with an autism spectrum disorder has support to accomplish goals at home.	☐	☐	☐	☐	☐
24.	My family member with an autism spectrum disorder has support to make friends.	☐	☐	☐	☐	☐
25.	My family has good relationships with the service providers who provide services and support to our family member with an autism spectrum disorder.	☐	☐	☐	☐	☐

Appendix B

Life Orientation Test–Revised (LOT–R)

DIRECTIONS: The following is a list of statements about how you view yourself. For each statement listed below, please **CIRCLE** the number that describes the extent to which you agree with that statement. Be as honest as you can and try not to let your responses to one question influence your response to other questions. There are no right or wrong answers.

		Strongly Disagree	**Disagree**	**Neither Disagree nor Agree**	**Agree**	**Strongly Agree**
1.	In uncertain times, I usually expect the best.	1	2	3	4	5
2.	It's easy for me to relax.	1	2	3	4	5
3.	If something can go wrong for me, it will	1	2	3	4	5
4.	I'm always optimistic about my future.	1	2	3	4	5
5.	I enjoy my friends a lot.	1	2	3	4	5
6.	It's important for me to keep busy.	1	2	3	4	5
7.	I hardly ever expect things to go my way.	1	2	3	4	5
8.	I don't get upset too easily.	1	2	3	4	5
9.	I rarely count on good things happening to me.	1	2	3	4	5
10.	Overall, I expect more good things to happen to me than bad.	1	2	3	4	5

Carver & Scheier, 2003

Appendix C

Multidimensional Health Locus of Control Scale – Form C

DIRECTIONS: Each item below is a belief statement about your child's autism spectrum disorder with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item, circle the number the represents the extent to which you agree or disagree with that statement. If you have more than one child diagnosed with an ASD, please answer the following focusing on only one of your children. Please circle only one number per item. Since this a measure of your personal beliefs, there are no right or wrong answers.

1 = STRONGLY DISAGREE (**SD**) 2= MODERATELY DISAGREE (**MD**) 3 = SLIGHTLY DISAGREE (**D**)	4 = SLIGHTLY AGREE (**A**) 5 = MODERATELY AGREE (**MA**) 6 = STRONGLY AGREE (**SA**)

		SD	**MD**	**D**	**A**	**MA**	**SA**
1.	If my child's autism spectrum disorder worsens, it is my own behavior which determines how soon he/she will do better again	1	2	3	4	5	6
2.	I am directly responsible for my child's autism spectrum disorder getting better or worse	1	2	3	4	5	6
3.	Whatever goes wrong with my child's autism spectrum disorder is my own fault	1	2	3	4	5	6
4.	The main thing which affects my child's autism spectrum disorder is what I myself do	1	2	3	4	5	6
5.	If my child's autism spectrum disorder take a turn for the worse, it is because I have not been taking proper care of her/him	1	2	3	4	5	6
6.	I deserve the credit when my child's autism spectrum disorder improves and the blame when it gets worse	1	2	3	4	5	6
7.	Most things that affect my child's autism spectrum disorder happen by chance	1	2	3	4	5	6
8.	Luck plays a big part in determining how my child's autism spectrum disorder improves.	1	2	3	4	5	6

1 = STRONGLY DISAGREE (**SD**) 2= MODERATELY DISAGREE (**MD**) 3 = SLIGHTLY DISAGREE (**D**)	4 = SLIGHTLY AGREE (**A**) 5 = MODERATELY AGREE (**MA**) 6 = STRONGLY AGREE (**SA**)

		SD	**MD**	**D**	**A**	**MA**	**SA**
9.	Whatever improvement occurs with my child's autism spectrum disorder is largely a matter of good fortune	1	2	3	4	5	6
10.	If my child's autism spectrum disorder worsens, it's a matter of fate.	1	2	3	4	5	6
11.	If I am lucky, my child's autism spectrum disorder will get better.	1	2	3	4	5	6
12.	As to my child's autism spectrum disorder, what will be will be.	1	2	3	4	5	6
13.	If my child sees professionals regularly, he/she is less likely to have problems with his/her autism spectrum disorder.	1	2	3	4	5	6
14.	Following professionals' advice to the letter is the best way to keep my child's autism spectrum disorder from getting worse	1	2	3	4	5	6
15.	Whenever my child's autism spectrum disorder worsen, I should consult a trained professional	1	2	3	4	5	6
16.	Other people play a big role in whether my child's autism spectrum disorder improve, stay the same, or get worse.	1	2	3	4	5	6
17.	The type of help I receive from other people determines how soon my child's autism spectrum disorder improves.	1	2	3	4	5	6
18.	In order for my child's autism spectrum disorder to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6

Wallston, Stein & Smith, 1994

Appendix D

Parental Concerns Questionnaire

DIRECTIONS: Autism spectrum disorders often have many behaviors associated with them. For each behavior listed below, please CIRCLE the number that describes the extent to which it has been a problem for your child **WITHIN THE PAST MONTH**. If you have more than one child diagnosed with an ASD, please answer the following focusing on only one of your children.

		No Problem	**Mild Problem**	**Moderate Problem**	**Severe Problem**
1	**Language use and understanding** (e.g., doesn't use words, has difficulty initiating conversations, etc.)	1	2	3	4
2	**Compulsive behaviors** (e.g., completes routines always in the same manner)	1	2	3	4
3	**Anxiety** (e.g., shows distress from new situations or crowds, etc.)	1	2	3	4
4	**Sensory issues** (e.g., reacts to lights, sounds, textures, etc.)	1	2	3	4
5	**Sleep disturbance** (e.g., does not fall asleep easily, wakes often, etc.)	1	2	3	4
6	**Aggression** (e.g., intentionally hits, bites others, etc.)	1	2	3	4
7	**Hyperactivity** (e.g., is constantly moving, running, jumping, etc.)	1	2	3	4
8	**Attention span** (e.g., has difficulty finishing a task, etc.)	1	2	3	4
9	**Mood swings** (e.g., has unpredictable changes between emotions)	1	2	3	4
10	**Eating habits** (e.g., eats few foods/certain types of foods, etc.)	1	2	3	4
11	**Social interactions** (e.g., prefers to be alone, has few friends, etc.)	1	2	3	4
12	**Self-stimulatory and repetitive behaviors** (e.g., rocks, spins, flap hand, etc.)	1	2	3	4
13	**Self-injurious behavior** (e.g., bangs head, pinches, bites, hits oneself, etc.)	1	2	3	4

Appendix E

Demographic Survey

Parent & Child Information

Please answer the following questions about yourself and your family by indicating the answer that is most like you and your family. Some questions may ask for additional information. Please provide as much as you feel comfortable.

1. How old are you? _____

2. What is your gender? M F

3. Which racial and/or ethnic group best describes you? (Select as many that apply)
   - ☐ White (non-Hispanic)
   - ☐ Asian or Asian-American
   - ☐ Black, African, or African-American
   - ☐ Hispanic or Latino (e.g., Puerto Rican, Mexican, Central or South American)
   - ☐ Middle Eastern
   - ☐ Pacific Islander
   - ☐ American-Indian, Eskimo
   - ☐ Black, Caribbean (e.g., Haitian, Jamaican)
   - ☐ Other: _____

4. What is your relationship to your child?
   - ☐ Biological father
   - ☐ Step-father
   - ☐ Foster father
   - ☐ Biological mother
   - ☐ Step-mother
   - ☐ Foster mother
   - ☐ Other biological caregiver (please note:_____)
   - ☐ Other non-biological caregiver (please note: _____)

5. What is the highest educational degree you have received?
   - ☐ Middle School
   - ☐ High School
   - ☐ Vocational or professional certificate and/or associate degree
   - ☐ Some college
   - ☐ 4 year college/University
   - ☐ Master's degree
   - ☐ Doctoral degree

6. What is your current marital status?
   - ☐ Single
   - ☐ Married
   - ☐ Widowed
   - ☐ Divorced
   - ☐ Separated
   - ☐ Domestic partner

7. What is your work status?
   - ☐ Full-time paid work outside of home
   - ☐ Part-time paid work outside of home
   - ☐ Full-time paid work from home
   - ☐ Part-time paid work from home
   - ☐ Stay at home caregiver

8. What is your family's total annual income?
   - ☐ Under $20,000
   - ☐ $20,000 - $39,999
   - ☐ $40,000 - $59,999
   - ☐ $60,000 - $79,999
   - ☐ $80,000 - $99,999
   - ☐ $100,000 - $124,999
   - ☐ $125,000 - $149,999
   - ☐ Over $150,000

9. How many children do you have? _____

10. How many children do you have with an autism spectrum disorder (ASD)? _____

Please answer the following questions about your child with an autism spectrum disorder (ASD). If you have more than one child with an ASD diagnosis, please focus on only one of your children:

11. How old is your child? _____

12. Child's gender: M F

13. Which racial and/or ethnic group best describes your ASD child? (Select as many that apply)
    - ☐ White (non-Hispanic)
    - ☐ Asian or Asian-American
    - ☐ Black, African, or African-American
    - ☐ Hispanic or Latino (e.g., Puerto Rican, Mexican, Central or South American)
    - ☐ Middle Eastern
    - ☐ Pacific Islander
    - ☐ American-Indian, Eskimo
    - ☐ Black, Caribbean (e.g., Haitian, Jamaican)
    - ☐ Other: _____

14. Child's diagnosis:
    - ☐ Asperger's Syndrome
    - ☐ PDD-NOS
    - ☐ Autism
    - ☐ Other, please specify: _____
    - ☐ Don't know

15. Age when first diagnosed: _____

16. Does your child currently live at home with you? Y N

Please answer the following questions about your child's services. If your child does not receive services in a particular category, leave the question blank or note "0 hours."

17. How many total hours of <u>specialized educational services</u> (i.e., specialized school placement or classroom support, early intervention, school-based PT/OT/ST, counseling) does your child receive **in** his/her educational setting **each week**?
    _____

18. How many total hours of behavioral services or "Wrap around" does your child receive **outside** of his/her educational setting (i.e, home or community) **each week**? _____

19. How many total hours of non-school related private therapy or services (e.g., private OT/PT/ST, counseling, hippotherapy, etc.) does your child receive **outside** of his/her educational setting **each week**? _____

20. If your child is an adult, how many total hours of adult-focused activities, services, or therapies does your child receive **each week**? _____

Overall, how satisfied have you been with your child's services in each of these four areas?

		Very Dissatisfied	*Dissatisfied*	*Neither Dissatisfied nor Satisfied*	*Satisfied*	*Very Satisfied*
21.	Educational Services	1	2	3	4	5
22.	Behavioral Services or "Wrap Around" Services	1	2	3	4	5
23.	Private Therapies or Services	1	2	3	4	5
24.	Adult-focused activities, therapy, or services	1	2	3	4	5

Many families of children diagnosed with an ASD have supplemented their child's behavioral and educational services with complementary or alternative treatments. These treatments include dietary restrictions (e.g., GFCF), dietary supplements (e.g., Omega-3, folic acid), and other complementary or alternative treatments (e.g., enzymes, melatonin, chelation) or medication.

25. Please list any complementary or alternative treatments that your child diagnosed with an ASD has **previously** used.

26. Please list any complementary or alternative treatments that your child diagnosed with an ASD is **currently** using.

27. Children diagnosed with different ASDs often present many challenges. Please identify the **one** developmental or behavioral area you feel that has had the most significant impact on your family.

28. How did you hear about this study?

- ☐ Listserv or Support Group
- ☐ School
- ☐ Service Provider
- ☐ Email
- ☐ Word of Mouth
- ☐ Other

29. Please provide your zip code. This is only for identifying the general area you live in and will not be used for any other purposes.

Zip Code: _____

Appendix F - Letter to Moderators of Internet Listserv Discussion Groups

To Whom It May Concern:

My name is Elizabeth Warter, a Ph.D. candidate in Counseling Psychology at Boston College and a parent of a child with autism. While I currently live in PA, I am working with Dr. Mary Walsh, a professor at Boston College, on my dissertation entitled "Promoting resiliency in families of individuals diagnosed with an autism spectrum disorder: The relationship between parental beliefs and family adaptation." The study seeks to better understand how parents' beliefs and experiences with their child diagnosed with an autism spectrum disorder (ASD) may influence their family's overall quality of life. I am hoping that information from this study may help better inform family-focused practice with families of ASD children.

I am contacting you to ask for your help. Specifically, I would like to have your permission to either directly contact the members of your group, or have you contact them, to ask for their participation in my study. I am contacting you first because I want to respect your members' privacy and do not want to spam them. I will not attempt to sell anything to your members.

The study entails participating in an anonymous Internet survey, which takes about 35-40 minutes to complete. While participants will not be directly compensated, they are able to be entered into a drawing for one of ten $50 gift certificates from their choice of WaWa, Amazon.com, Target, or Wal-Mart.

If you would, please look at the attached letter and decide if I can have your permission to send it to your members. Also, please feel free to look at the survey prior to your decision. Copies of the consent form and survey have been included for your review. The web address for the survey is currently inactive pending the start of this study. Both versions (i.e., online and paper) have identical content.

Please feel free to contact me at this email address or phone number if you have any further questions. At the conclusion of my study, I would be more than happy to make my findings available to you in a format that you would prefer. Thank you so much for your time!

Sincerely,

Elizabeth Warter, M.A.
Boston College
hilled@bc.edu
617-821-4234

Appendix G - Letter to Specialized Schools and Provider Organization Administrators

Dear [Administrator's Name]:

My name is Elizabeth Warter, a Ph.D. candidate in Counseling Psychology at Boston College and a parent of a child with autism. While I currently live in PA, I am working with Dr. Mary Walsh, a professor at Boston College, on my dissertation entitled "Promoting resiliency in families of individuals diagnosed with an autism spectrum disorder: The relationship between parental beliefs and family adaptation." My dissertation study seeks to better understand how parents' beliefs and experiences with their child diagnosed with an autism spectrum disorder (ASD) may influence their family's overall quality of life. I am hoping that information from this study can be used to inform family-focused practice with families of ASD children.

I am contacting you to ask for your help. Specifically, I would like permission to access families for my research through [organization or school name]. I am asking for your help to access families so that their anonymity can be protected and their privacy respected. I will not attempt to sell anything to your families. To protect families' privacy, my research study is using two data collection procedures. The first has organizations directly send a paper survey packet, provided by me, home to their families. The second has organizations send a letter or email directly home to families inviting them to participate in the web-based version of this study. By having organizations send this information home to families directly, it allows for their anonymity to be protected; all costs for contacting families will also be assumed by me.

I have attached a copy of my letter to parents, the consent form they would receive, as well as the measures I am using in my study. This is the paper protocol; the on-line (web-based) survey has identical content, but varies slightly in the visual format.

The letter to parents describes the purpose of the study and asks them to consider participating. Participation in this study takes about 35-40 minutes and can be done either via the internet or paper survey. While participating parents will not receive reimbursement for their time, those who complete either an online version of this study or the paper version of this survey may choose to be entered into a drawing for one of ten $ 50 gift certificates from their choice of WaWa, Amazon.com, Target, or Wal-Mart.

If you would, please look at the attached letter and decide if I can have your permission to use your organization to access potential participants. Also, please feel free to look at the survey prior to your decision. As noted, a copy of the consent form and survey has been included for your review. An online version can also be accessed by families, but is currently inactive pending the start of this study.

Please feel free to contact me at this email address or the contact information provided below if you have any further questions, concerns, or if you would like to discuss this further. If you do decide to help me access families, please let me know how you would like to proceed and which data collection procedure would be best for your [school/organization]. At the conclusion of my study, I would be more than happy to make my findings available to you in a format that you would prefer.

Thank you so much for your time and consideration!

Sincerely,

Elizabeth Warter, M.A.
Boston College
hilled@bc.edu
(cell) 617-821-4234
(home) 484-341-8015

Appendix H - Request for Participants Posted on Listservs and Support Groups

Subject: Call for parents of ASD children to participate in survey and chance to win $50 gift certificate

My name is Elizabeth Warter and I am both a Ph.D. candidate in Counseling Psychology at Boston College as well as a parent of an autistic child. Your listserv or support group has agreed to send this message on my behalf. I am currently completing my dissertation research on the experiences of families of children diagnosed with an autistic spectrum disorder (ASD), under the direction of Mary Walsh, Ph.D. I am writing to this group to ask for your participation in my online research survey and to offer you an opportunity to be entered into a random drawing for one of ten $50 gift certificates from either WaWa, Amazon.com, Target or Wal-Mart.

The experience of caring for a child with an autism spectrum disorder (ASD) has been related to a number of individual outcomes, both positive and negative, for caretakers and siblings. However, the relationship between experiences related to a child's ASD, parents' view of their world and their ASD-related experiences, and family outcomes has not been well studied. My research is an attempt to further our understanding of family's experiences with autism. I hope that information gained from this study may help inform family-focused interventions and treatment with families of children diagnosed with an ASD.

I am asking parents of a child diagnosed with an ASD to consider participating in this study. You are eligible to participate if you are at least 18 years of age and have a child over the age of two who has been diagnosed with one of three types of ASDs: Pervasive Developmental Disorder (PDD-NOS), Autism, or Asperger's Syndrome (AS).

Your survey responses are entirely anonymous. Any name and email address information you choose to provide will not be tied in any way to your responses. This information will only be used for the drawing and will be completely destroyed once the drawing is completed. Your identifying information will not be used in any other way except that which has already been stated.

In the survey you will be asked some questions about your satisfaction with your family's quality of life; your general views of the world and specific views regarding your child's ASD; and your child's behaviors and aspects related to his/her diagnosis; and some questions about yourself and your child, including such information as age, race/ethnicity, and gender, as well as amount of, and satisfaction with, your child's current services. The survey takes approximately 35-40 minutes to complete and can be found online at: https://www.psychdata.com/s.asp?SID=124732. Alternatively, you can

go to http://www.psychdata.com and in the box that states "Go to Survey #" and type "124732".

At the completion of the survey, you can also choose to participate in a drawing for 1 of 10 $50 gift certificates to your choice of WaWa, Amazon.com, Target, or Wal-Mart, drawn at random from the participants who complete the survey. While this survey is open to all parents, thus both mothers and fathers are encouraged to participate, please complete only one survey per person.

If you have questions about the study, I can be contacted by email at hilled@bc.edu or by phone at 617-821-4234 to answer any questions. You may also contact Dr. Walsh by phone at 617-552-8973 or email at walshhur@bc.edu. If at any time you have questions or concerns about your rights as a participant in a research study, please contact the Boston College Office for Human Research Participant Protection at (617) 552-4778. If you would like to receive a copy of the results of this study, please email me at the below address. Results will be distributed at the conclusion of the study.

Thank you for your consideration!

Elizabeth Warter, M.A.
Boston College
hilled@bc.edu
617-821-4234

Mary Walsh, Ph.D.
150 Commonwealth Avenue
Campion Hall
Boston College
Chestnut Hill, MA 02467
walshhur@bc.edu
617-552-8973

Appendix I – Web-based Survey Start page, Consent Form, and Debriefing

Start Page:

Survey #124732
Help?

Please select the appropriate choice:

☐ **New Participants –** This is the first time you are answering questions to this survey.

This survey is configured to let you save your work and continue later. To save your progress, be sure that you have completely finished the page you are on and then click on the "Save and Exit" button on the bottom of the page. Click here to print these instructions.

Email Address:

Create Password:

Submit

☐ **Returning Participants –** Welcome back! You will begin where you previously left off.

Enter Email Address:

Enter Your Password: (Forgot Password?)

Submit

Boston College Consent Form

Introduction
You are being invited to take part in a research study conducted by Elizabeth Warter, M.A. (Ph.D. candidate in Counseling Psychology) at Boston College, under the direction of Mary Walsh, Ph.D. The title of this research study is "Promoting resiliency in families of individuals diagnosed with an autism spectrum disorder: The relationship between parental beliefs and family adaptation." The study seeks to better understand how parents' beliefs and experiences with respect to their child diagnosed with an autism spectrum disorder (ASD) may influence their family's overall quality of life. To participate in this study, you must be 18 years of age or older and have a child who has been diagnosed with an autism spectrum disorder (i.e., diagnosis of Pervasive Developmental Disorder [PDD-NOS], Autism, or Asperger's Syndrome [AS]). We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study:
The purpose of this study is to better understand the relationship between parents' beliefs and general views and their family's quality of life. The total number of participants is expected to be approximately 150 individuals.

Description of the Study Procedures:
Taking part in the study means completing a survey one time. Answering the survey's questions should take about 35-40 minutes to complete. In the first part of the survey, you will be asked questions regarding your satisfaction with your family's quality of life. Then you will be asked questions about your general views of the world and specific views regarding your child's ASD. Then you will be asked questions about your child's behaviors and aspects related to his/her diagnosis. Finally, you will be asked questions about yourself and your child, including such information as age, race/ethnicity, and gender, as well as amount of, and satisfaction with, your child's current services.

Risks/Discomforts of Being in the Study:
Participating in the study should involve no more risks than you find in everyday life. However, if you experience any discomfort while completing the questions, you are free to discontinue participation without penalty. While it is not possible to identify all possible risks, all reasonable efforts have been taken to minimize such potential risks (e.g., by protecting your anonymity).

Benefits of Being in the Study:
While there are no immediate benefits to your particular family, we hope that information gained from this study may help inform family-focused interventions and treatment with families of children diagnosed with an autism spectrum disorder (ASD) in the future.

Payments:
While you will not receive direct reimbursement for participating in this study, you can choose to be entered into a drawing at the completion of this study. The drawing will randomly select 10 participants to each receive a $50 gift certificate to their choice of one of the following: WaWa, Amazon.com, Target, or Wal-Mart.

Costs:
There is no cost to you to participate in this research study.

Confidentiality:
In this study your answers will be anonymous. Although you will be asked to give your name and email address in order to be entered into the drawing, you can choose not to participate in the drawing and remain fully anonymous. If you choose to participate in the drawing, your name and email address will only be used to purchase a gift certificate and to contact you should you win. Your name and email address will be separated electronically from your survey responses and later deleted entirely from the data file once the drawing has taken place. There will be no paper record of your name and email address. Deletion of your name and email address from the data file will occur soon after the total number of participants has been satisfied, but no later than December 1, 2008. In this way, the survey responses you provide will never be linked to your name. This research may be published or reported on, but the data in any such presentation or publication will be reported in a group format (i.e., group averages will be reported, not any individual's specific scores). Access to the records of this study will be limited to researchers; however, please note that the Institutional Review Board and internal Boston College auditors may review the research records.

Voluntary Participation/Withdrawal:
Your participation is purely voluntary and you are free to withdraw your consent and to discontinue participation at any time, for any reason, without penalty or loss of benefits.

Contacts and Questions:
If you have questions about the study, Elizabeth Warter, M.A. can be contacted by phone at 617-821-4234 or email at hilled@bc.edu to answer any questions. You may also contact Dr. Mary Walsh by phone at 617-552-8973 or email at walshhur@bc.edu. If at any time you have questions or concerns about your rights as a participant in a research study, please contact: Director, Office for Human Research Participant Protection, Boston College at (617) 552-4778, or irb@bc.edu.

Copy of Consent Form:
If you believe you understand the issues addressed above, particularly the risks, issues of confidentiality, and what you are being asked to do, please click on the **Continue to Next Page** button to indicate that you consent to participate in this study. If you do not understand this information or need to ask questions about the study prior to beginning, please contact Elizabeth Warter at 617-821-4234 or hilled@bc.edu. You may also contact Dr.Mary Walsh by phone at 617-552-8973 or email at walshhur@bc.edu. Please feel free to print out a copy of this page to keep as a record.

Debriefing

Thank you for completing this survey! The experience of caring for a child with an autism spectrum disorder (ASD) has been related to a number of individual outcomes, both positive and negative, for caretakers and siblings. However, the relationship between experiences of stress related to a child's ASD, parents' view of their world and their ASD-related experiences, and family outcomes has not been well studied. The purpose of this study is to examine how caretakers' beliefs influence the family's overall quality of life, as well as how these beliefs influence the impact specific ASD-related stressors have on their family's quality of life.

If you have questions about the study, Elizabeth Warter can be contacted by phone at 617-821-4234 or email at hilled@bc.edu. If at any time you have questions or concerns about your rights as a participant, you can contact the Boston College Office for Human Research Participant Protection at (617) 552-4778.

Thank you very much for your participation! Please fill in the following if you wish to be entered into the drawing for 1 of 10 $50 gift certificates to either WaWa, Amazon.com, Target, or Wal-Mart. When done, please click on the **Continue to Next Page** button to enter your information into the drawing. If you are not interested in being entered into the drawing, please close your browser window to finish your participation.

First Name:

Last Name:

Email address:

Continue to Next Page

You are Done!

… AND you have been entered into the drawing and will be contacted no later than October 1, 2008, if you are a winner of a $50 gift certificate! However, even if you do not win, please know that your responses have been extremely helpful in furthering our understanding of the experiences of families of individuals diagnosed with an autism spectrum disorder (ASD).

Thanks for Participating!

Appendix J - Request for Participants Sent Home by Administrators

To Whom It May Concern:

My name is Elizabeth Warter and I am both a Ph.D. candidate in Counseling Psychology at Boston College as well as a parent of an autistic child. Your child's [school or service provider] has agreed to send this letter and survey packet to you on my behalf. I am currently completing my dissertation research on the experiences of families of children diagnosed with an autistic spectrum disorder (ASD), under the direction of Mary Walsh, Ph.D. I am writing to you to ask for your participation in my research survey and to offer you an opportunity to be entered into a random drawing for one of ten $50 gift certificates from WaWa, Amazon.com, Target or Wal-Mart.

The experience of caring for a child with an autism spectrum disorder (ASD) has been related to a number of individual outcomes, both positive and negative, for caretakers and siblings. However, the relationship between experiences related to a child's ASD, parents' view of their world and their ASD-related experiences, and family outcomes has not been well studied. My research is an attempt to further our understanding of family's experiences with autism. I hope that information gained from this study may help inform family-focused interventions and treatment with families of children diagnosed with an ASD.

I am asking parents of a child diagnosed with an ASD to consider participating in this study. You are eligible to participate if you are at least 18 years of age and have a child over the age of two who has been diagnosed with one of three types of ASDs: Pervasive Developmental Disorder (PDD-NOS), Autism, or Asperger's Syndrome (AS).

Your survey responses are entirely anonymous. Any name, email, or address information you choose to provide will not be tied in any way to your responses. This information will only be used for the drawing and will be completely destroyed once the drawing is completed. Your identifying information will not be used in any other way except that which has already been stated. As noted above, this research study is independent from your child's [school or service provider] and will have no impact upon your child's services.

In the survey you will be asked some questions regarding your satisfaction with your family's quality of life; your general views of the world and specific views regarding your child's ASD; your child's behaviors and aspects related to his/her diagnosis; and some questions about yourself and your child, including such information as age, race/ethnicity, and gender, as well as amount of, and satisfaction with, your child's current services. The survey takes approximately 35-40 minutes. A copy of the survey is enclosed with this letter. For your convenience, this survey can also be found online at: https://www.psychdata.com/s.asp?SID=124732. Alternatively, you can go to

http://www.psychdata.com and in the box that states "Go to Survey #" and type "124732".

At the completion of the survey, you can also choose to participate in a drawing for 1 of 10 $50 gift certificates to your choice of WaWa, Amazon.com, Target, or Wal-Mart, drawn at random from the participants who complete the survey. While this survey is open to all parents, thus both mothers and fathers are encouraged to participate, please complete only one survey (either paper or web-based) per person.

If you have questions about the study, please contact me by email at hilled@bc.edu or by phone at 617-821-4234 so that I can answer any questions. You may also contact Dr. Walsh by phone at 617-552-8973 or email at walshhur@bc.edu. If at any time you have questions or concerns about your rights as a participant in a research study, please contact the Boston College Office for Human Research Participant Protection at (617) 552-4778. If you would like to receive a copy of the results of this study, please email me at the below address. Results will be distributed at the conclusion of the study.

Thank you for your consideration!

Elizabeth Warter, M.A.
Boston College
hilled@bc.edu
617-821-4234

Mary Walsh, Ph.D.
150 Commonwealth Avenue
Campion Hall
Boston College
Chestnut Hill, MA 02467
walshhur@bc.edu
617-552-8973

Appendix K – Paper Survey Consent Form

Boston College Consent Form

Introduction
You are being invited to take part in a research study conducted by Elizabeth Warter, M.A. (Ph.D. candidate in Counseling Psychology) at Boston College, under the direction of Mary Walsh, Ph.D. The title of this research study is "Promoting resiliency in families of individuals diagnosed with an autism spectrum disorder: The relationship between parental beliefs and family adaptation." The study seeks to better understand how parents' beliefs and experiences with respect to their autism spectrum disorder (ASD) child may influence their family's overall quality of life. To participate in this study, you must be 18 years of age or older and have a child who has been diagnosed with an autism spectrum disorder (i.e., diagnosis of Pervasive Developmental Disorder [PDD-NOS], Autism, or Asperger's Syndrome [AS]). We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study:
The purpose of this study is to better understand the relationship between parents' beliefs and general views and their family's quality of life. The total number of participants is expected to be approximately 150 individuals.

Description of the Study Procedures:
Taking part in the study means completing a survey one time. Answering the survey's questions should take about 35-40 minutes to complete. In the first part of the survey, you will be asked questions regarding your satisfaction with your family's quality of life. Then you will be asked questions about your general views of the world and specific views regarding your child's ASD. Then you will be asked questions about your child's behaviors and aspects related to his/her diagnosis. Finally, you will be asked questions about yourself and your child, including such information as age, race/ethnicity, and gender, as well as amount of, and satisfaction with, your child's current services.

Risks/Discomforts of Being in the Study:
Participating in the study should involve no more risks than you find in everyday life. However, if you experience any discomfort while completing the questions, you are free to discontinue participation without penalty. While it is not possible to identify all possible risks, all reasonable efforts have been taken to minimize such potential risks (e.g., by protecting your anonymity).

Benefits of Being in the Study:
While there are no immediate benefits to your particular family, we hope that information gained from this study may help inform family-focused interventions and treatment with families of children diagnosed with an autism spectrum disorder (ASD) in the future.

Payments:
While you will not receive direct reimbursement for participating in this study, you can choose to be entered into a drawing at the completion of this study. The drawing will randomly select 10 participants to each receive a $50 gift certificate to their choice of one of the following: WaWa, Amazon.com, Target, or Wal-Mart.

Costs:
There is no cost to you to participate in this research study.

Confidentiality:
In this study your answers will be anonymous. If you choose to participate in this study, this signed consent form will be separated from your survey packet as soon as it is received. This paper consent form will be stored separately from the survey data and will only be utilized to identify participants interested in participating in the drawing. The survey responses you provide will never be linked to your name. Although you will be asked to give your name, email (if applicable) and address in order to be entered into the drawing, you can choose not to participate in the drawing and not provide your address information. If you choose to participate in the drawing, your name, email (if applicable), and address will only be used to purchase a gift certificate and to contact you should you win. This research may be published or reported on, but the data in any such presentation or publication will be reported in a group format (i.e., group averages will be reported, not any individual's specific scores). Access to the records of this study will be limited to researchers; however, please note that the Institutional Review Board and internal Boston College auditors may review the research records.

Voluntary Participation/Withdrawal:
Your participation is purely voluntary and you are free to withdraw your consent and to discontinue participation at any time, for any reason, without penalty or loss of benefits.

Contacts and Questions:
If you have questions about the study, Elizabeth Warter, M.A. can be contacted by phone at 617-821-4234 or email at hilled@bc.edu to answer any questions. You may also contact Dr. Mary Walsh by phone at 617-552-8973 or email at walshhur@bc.edu. If at any time you have questions or concerns about your rights as a participant in a research study, please contact: Director, Office for Human Research Participant Protection, Boston College at (617) 552-4778, or irb@bc.edu.

Statement of Consent:
I have read the contents of this consent form and understand the issues addressed above, particularly the risks, issues of confidentiality, and what you are being asked to do. I have received answers to any questions I might have and give my consent to participate in this study. I have received and retained an additional copy of this form for my records.

Study Participant (Print Name) : _____

Participant Signature: _____ Date _____

If you wish to participate in the drawing for one of ten $50 dollar gift certificates, please provide additional information below so that we may contact you if you are randomly picked for a drawing prize:

Email Address (if applicable): _____

Address: _____

_____